PATIENT EXPERIENCES AT A HIGH-RISK PANCREATIC CANCER CLINIC: A THEMATIC ANALYSIS OF FOCUS GROUPS

by

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ABSTRACT

Pancreatic cancer is a rare, occurring in less than 2% of the population, but high mortality disease with a survival rate of less than 6%. Approximately 5-10% of pancreatic cancer is due to a hereditary predisposition. A hereditary predisposition may be due to a pathogenic variant within a gene related to cancer syndromes, or some individuals may also be at risk due to having two or more first-degree relatives or three or more close family members who have been diagnosed with pancreatic cancer, which is considered Familial Pancreatic Cancer. This study focuses on these individuals who are at an increased risk of developing pancreatic cancer and their caregivers. The goal of this study is to identify patients' experiences at a high-risk pancreatic cancer center in Pittsburgh, Pennsylvania, and their experiences of living with a family history of pancreatic cancer.

Participants of the larger Pancreatic Adenocarcinoma Gene Environment Risk (PAGER) Study and their caregivers were invited to attend one of two focus groups where they were able to provide their opinions and comments about the clinic and their feelings of living with an increased risk of pancreatic cancer.

Transcripts of the focus groups were analyzed by qualitative thematic analysis, which identified five major themes. The main themes identified were: 1. Attributes study participants

noted about the clinic staff; 2. Barriers individuals faced to receiving care; 3. The fear participants described related to being at an increased risk to develop pancreatic cancer; 4. The family dynamics surrounding the increased risk for pancreatic cancer; and 5. Areas of improvement identified by participants for the clinic and pancreatic cancer research in general.

The results of this study identified overwhelming satisfaction with the UPMC High-Risk Pancreas Clinic and the care that is provided to the patients in the clinic. Public Health Significance: This study has public health significance because it has been shown that patients who are satisfied with their care experience better health outcomes.

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PREFACE

I would like to take this opportunity to thank my thesis committee for their guidance throughout this process. I would also like to give a special thanks to Beth Dudley, MS, CGC for being my liaison with the High-Risk Clinic.

To my classmates, thank you for all of the support throughout our time here in Pittsburgh. Having you ladies by my side made this trek a lot more interesting, in the best way possible.

I cannot express my sincerest gratitude to all my friends and family back home in the "Motherland." Thank you for all of the support throughout the years, especially while I was away. Mom and Dad, thank you for always being my quiet cheerleaders, always supporting me and my dreams. Lastly, I need to thank my more vocal cheerleaders, my nieces, Rachel and Miriam, and nephews, Peter and Max. Your great enthusiasm always reminds me the importance of having fun!

1.0 INTRODUCTION

Pancreatic cancer is a rare form of a cancer with a high mortality rate. The significant mortality rate is due to the difficulty in making a diagnosis at an early stage of the disease when surgery to remove and help cure the cancer would be most effective (Brand et al., 2007). Even at later stages of the disease, symptoms tend to be non-specific and remain difficult to accurately diagnose (Brand et al., 2007). Because of the rarity of pancreatic cancer, there are no guidelines for general population screening such as those that are in place for breast and colon cancers. Even for those with a demonstrably higher risk of developing pancreatic cancer, a robust screening plan has not been implemented (Brand et al., 2007; Syngal et al., 2015). Given these limitations, there is agreement that utilizing endoscopic ultrasound and abdominal MRI imaging techniques improve the early detection of cancers or precancerous lesions (Brand et al., 2007; Syngal et al., 2015).

The High-Risk Pancreatic Clinic at UPMC Shadyside in Pittsburgh, Pennsylvania is a clinical service available to high-risk individuals where they can be closely monitored. In addition to increased screening, patients seen in the clinic are offered genetic counseling and testing when appropriate to help identify the presence of a pathogenic variant that may increase the patient's risk of developing cancer. Furthermore, patients are provided with the option to receive quarterly bulletins about new research and updates in the clinic. As well, they have the

opportunity to participate in research studies, such as the Pancreatic Adenocarcinoma Gene Environment Risk (PAGER) Study.

One benefit of such a clinical program in the community is that it encourages patients to be proactive about their health, and facilitates an ongoing relationship between patients and health care providers. Exceptional patient health care encompasses more than physical treatment. It also includes demonstrating an understanding of how patients may feel about a treatment plan or their risks for a disease, and listening to any concerns they may have. By demonstrating a willingness to communicate effectively with patients, clinicians can provide a health care environment that invites patients to be more involved in their own health matters, and therefore be more willing to continue seeking treatment. The purpose of this study is to evaluate the experiences of patients within the High-Risk Pancreatic Clinic. The overall purpose of this research study is to better understand the needs, expectations, and opinions of the patient population of the High-Risk Pancreas Clinic. In addition, we are interested in understanding the medical and psychosocial issues of having a family history of pancreatic cancer.

2.0 BACKGROUND

2.1 THE PANCREAS

The pancreas is an abdominal organ with both exocrine and endocrine functions in the human body. Acinar cells are a part of the exocrine pancreas that produce digestive enzymes and comprise around 90% of all pancreatic cells (Schwab, 2011). Islets of Langerhans cells are endocrine cells that are interspersed throughout the pancreas that function to regulate glucose levels by producing and excreting insulin (Schwab, 2011).

2.2 PANCREATIC CANCER

According to the American Cancer Society, in 2015 there were about 48,960 new diagnoses of pancreatic cancer, and approximately 40,560 deaths due to this disease (ACS, 2016). The chance for individuals in the general population to develop pancreatic cancer during their lifetime is less than 2% (ACS, 2016). In the United States, about 3% of all diagnosed cancers are pancreatic, and about 7% of all cancer deaths are due to pancreatic cancer (ACS, 2016). The mortality rate is the highest for pancreatic cancer, with less than a 7% five-year survival rate (ACS, 2016). Survival rates for pancreatic cancer have not shown much improvement over the past 40 years (Howell et al., 2013). Unfortunately, due to the close proximity of the pancreas to other organs as

well as the high vascularity, cancers of the pancreas are prone to metastatic disease and are not easily resected (Schwab, 2011).

Studies have examined the predicted length of time from when a tumor in the pancreas begins to grow until the time of diagnosis, with one study identifying up to a 17-year period between tumor onset and correct diagnosis (Tewari, 2015; Yachida et al., 2010). Many hypothesize metastatic disease occurs years after the original pancreatic primary (Tewari, 2015). However, there is also a theory that metastatic disease occurs early on in the tumorigenesis process and thus, the metastatic process is occurring in concert with the pancreatic tumor formation (Rhim et al., 2012; Tewari, 2015).

More than 90% of pancreatic cancers are adenocarcinomas, with most originally occurring from duct cells or stem cells (Brand et al., 2007). Genetic changes in adenocarcinomas have been described. About 90% of pancreatic cancers have an active K-*ras* oncogene, and tumor suppressor genes commonly altered include *p16 (*27-98%*) p53* (40-75%), and *MADH4* (55%) (Brand et al., 2007).

2.2.1 Types of Pancreatic Cancer

There are three pancreatic lesions that can become cancerous: intraductal papillary mucinous neoplasm (IPMN), mucinous cystic neoplasia (MCN), and pancreatic intra-epithelial neoplasia (PanIN) (Brand et al., 2007; Stoita et al., 2011). Early detection and treatment for IPMNs and MCNs are possible before they become cancerous (Brand et al., 2007). The most common lesion is PanIN (Stoita et al., 2011). Lesions within the main duct IPMN are more likely to be malignant compared to lesions identified within the branch duct IPMN (Stoita et al., 2011).

There are three grades of PanIN; with PanIN-1 being low-grade dysplasia to PanIN-3 being high-grade dysplasia (Stoita et al., 2011). High-grade lesions as well PanINs and IPMNs in general are more commonly found in patients who have a strong family history of pancreatic cancer than those who have a seemingly sporadic diagnosis (Shi et al., 2009; Stoita et al., 2011). Endoscopic ultrasounds (EUS) provides the best detection for small MCN, branch duct IPMN, and chronic pancreatitis and CT and MRI are capable of identifying main duct IPMN and large MCN (Stoita et al., 2011).

2.2.2 Pancreatic Cancer Risk Factors

Eighty percent of pancreatic cancer diagnoses happen between 60 and 80 years of age (Brand et al., 2007). Men, people of Ashkenazi Jewish (Eastern European) decent, and those who are of African ancestry are also at an increased risk of developing pancreatic cancer (Brand et al., 2007).

Having a genetic predisposition for pancreatic cancer confers the greatest risk for an individual (Brand et al., 2007). Although in some families there is an autosomal dominant pattern of inheritance, there may not be an identifiable pathogenic variant that is causing this inheritance pattern (Brand et al., 2007).

Eighty percent of patients with pancreatic cancer have also been identified to have diabetes or impaired glucose tolerance; however, a clear association between diabetes and pancreatic cancer has yet to be consistently determined (Brand et al., 2007). Smoking has been identified as a risk factor for pancreatic cancer and patients who have a genetic predisposition should quit smoking when possible (Brand et al., 2007). Living a healthy life by eating a diet high in fruits and vegetables, limiting red and processed meats and staying active will help in

reducing risk as people who are obese and are sedentary are at a higher risk of developing pancreatic cancer (Brand et al., 2007; Michaud et al., 2014). Additionally, individuals with a *Helicobacter pylori* infection have a twofold risk of developing pancreatic cancer (Brand et al., 2007; Stolzenberg-solomon et al., 2001). Individuals who have cystic fibrosis have a 2.6- to 32-fold increased risk and individuals with chronic pancreatitis have a 16.5- to 19-fold increased risk of developing pancreatic cancer (Brand et al., 2007; Lowenfels et al., 1993; Maisonneuve et al., 2003). A 50-fold increased risk was identified for patients with hereditary pancreatitis (Brand et al., 2007; Howes et al., 2004; Lowenfels et al., 1997).

2.2.3 Genetics

The majority of pancreatic cancer cases are sporadic; however 5-10% can be familial and in 10-20% of these cases there is an identifiable genetic component (Greer et al., 2009). Cancer syndromes related to an increased risk for pancreatic cancer include Peutz-Jeghers Syndrome (PJS; *STK11*) (Su et al., 1999), pathogenic variants in the *ATM* and *PALB2* genes (Underhill et al., 2015), Familial Atypical Multiple Mole Melanoma (*CDKN2A*) (Goldstein et al., 1995), Hereditary Breast and Ovarian Cancer (*BRCA1*) (Brose et al., 2002) and (*BRCA2*) (Easton & Consortium, 1999), Familial Adenomatous Polyposis (*APC*) (Giardiello et al., 1993), and Hereditary Nonpolyposis Colorectal Cancer, also known as Lynch Syndrome (*MLH1, MSH2, MSH6,* and *PMS2*) (Watson & Lynch, 1993). Pathogenic variants within the above mentioned genes confer variable risks anywhere from a 5-36% lifetime risk of developing pancreatic cancer (Greer et al., 2009). For example, Hall et al. (2008) compared patients with similar BRCAPRO cancer risks, and found that those who had a close relative with pancreatic cancer were also at a three- to four-fold risk of possessing a pathogenic variant in either *BRCA1* or *BRCA2* genes.

Individuals with a pathogenic variant in the *STK11* gene have the highest risk of developing pancreatic cancer with a 132-fold increased risk (Giardiello et al., 2000). Pathogenic variants within the *CDKN2A* gene confer a 12- to 39-fold increased risk of developing pancreatic cancer (Borg et al., 2000; Goldstein et al., 1995; Vasen et al., 2000). Having a pathogenic variant in one of the Lynch genes gives individuals a 9- to 11-fold increased risk (Syngal et al., 2015; Win et al., 2012). Pathogenic variants in *APC* have a 5-fold increased risk (Giardiello et al., 1993). Individuals who have a *BRCA1* mutation have a lower risk of developing pancreatic cancer as compared to the counterparts who have a *BRCA2* mutation, each having a 2-fold and 3- to 9-fold increased risk, respectively (Brose et al., 2002; Thompson & Easton, 2002; van Asperen et al., 2005). In the *ATM* gene, pathogenic variants confer a 3-fold increased risk of developing pancreatic cancer (Geoffroy-Perez et al., 2001). While it is known that risks are increased for individuals who have a pathogenic variant in *PALB2*, the level of risk is not known (Syngal et al., 2015).

Because there is a genetic component that can contribute to the development of pancreatic cancer, genetic testing is available for these known cancer syndromes and genes. However, because not all of the genes related to pancreatic cancer have been identified, a negative genetic test is not necessarily completely informative unless there is a known familial pathogenic variant.

2.2.4 Familial Pancreatic Cancer

Familial pancreatic cancer is defined as having two or more first-degree relatives with pancreatic cancer and no further genetic cause has been identified (Brand et al., 2007). For families with no identifiable pathogenic variant, risks of developing pancreatic cancer increase by the degree of

relatedness and the number of affected relatives. A dramatic increase in risk is noted when an individual has one first-degree relative with pancreatic cancer. The risk increases to approximately 6% with one first-degree relative and up to approximately 40% when there are three or more affected first-degree relatives (Greer et al., 2009; Howell et al., 2013). The number of first- and second-degree family members with pancreatic cancer plays a role in one's risk of developing pancreatic cancer (Lewis et al., 2009). A patient with three or more relatives or two or more first-degree relatives with pancreatic cancer are considered to be at high risk with a 4- to 32-fold increased risk of developing pancreatic cancer (Brune et al., 2010; Klein et al., 2004; Underhill et al., 2015). Additionally, anticipation has been noted within these families where each subsequent generation is diagnosed earlier than the last (Greer et al., 2009).

2.3 SCREENING AND TREATMENT

Screening protocols for several types of cancer have been established by various organizations such as the American Cancer Society and the National Cancer Consortium Network (NCCN). However, currently there are no guidelines in place for pancreatic cancer screening for the general population, nor is it recommended because of the low incidence rate and the lack of empirical evidence demonstrating an increase in survival resulting from screening (Canto et al., 2013; Lewis et al., 2009; Rulyak & Brentnall, 2004; Vitone et al., 2006). Diagnosing pancreatic cancer can prove to be difficult based on symptoms alone due to their commonality in nature, which include epigastric pain, weight loss, and obstructive jaundice (Brand et al., 2007). Unfortunately, many of these symptoms indicate a later stage of disease (Brand et al., 2007), underscoring the importance of increased screening for individuals at a high risk.

2.3.1 Screening

Current methods of screening for pancreatic cancer are computer tomography (CT), magnetic resonance imaging (MRI), and endoscopic ultrasound (EUS) (Howell et al., 2013). The majority of current screening modalities do not have the ability to detect tumors that are small, less than one centimeter, and do not have lymph node involvement so they can be removed resulting in a better long-term survival rate (Brand et al., 2007). The survival rate is the same for all patients who have a tumor identified to be larger than one centimeter (Brand et al., 2007). EUS does the best job in identifying tumors that are smaller than one centimeter so many centers choose this as their preferred screening modality (Brand et al., 2007; Matsubayashi, 2011).

While there are no formal guidelines for screening patients at an increased risk of developing pancreatic cancer, there is expert opinion on utilizing some modalities that have been found to help identify pancreatic dysplasia and there is more support in implementing these screening methods for high-risk individuals (Breitkopf et al., 2012; Syngal et al., 2015). Rulyak and Brentnall (2004) suggest utilizing endoscopic ultrasound (EUS) as a first step in screening and following up on any abnormal findings with endoscopic retrograde cholangiopancreatography (ERCP) for confirmation. Rulyak and Brentnall (2004) further describe the risk-benefit considerations with EUS screening and recommend that screening be done only if the patient would opt to undergo surgery should cancer be diagnosed, and suggest that screening start at age 50, or 10 years earlier than the youngest diagnosis (Syngal et al., 2015). It has also been argued that due to anticipation, screening can begin earlier at 40-45 years of age or 15 years earlier than the first diagnosis (Brand et al., 2007; Canto et al., 2013; Matsubayashi, 2011). Of note, it is recommended that screening start at age 30-35 for patients with PJS, as the average age of onset tends to be younger at about 40 years old (Canto et al.,

2013; Matsubayashi, 2011; Syngal et al., 2015). There is still debate for the best screening intervals, generally ranging from one to three years, with some recommending a case-by-case decision for what is best for the patient (Brand et al., 2007). Screening may be increased to every three months to one year when any abnormal findings are detected (Matsubayashi, 2011). EUS screening may not be the best test for patients with chronic pancreatitis or chronic alcohol use as they present in a similar fashion (Brand et al., 2007; Rulyak & Brentnall, 2004). Vitone et al. (2006) emphasize the importance of high positive predictive values and negative predictive values when evaluating screening modalities. The first step of screening, as recommended by the International Cancer of Pancreas Screening Consortium is EUS or MRI and if cancer is identified, then a referral to a high-risk pancreatic cancer center for further follow-up (Canto et al., 2013; Underhill et al., 2015).

It is recommended that any individual who is at a greater than tenfold risk of developing pancreatic cancer should undergo screening (Brand et al., 2007; Matsubayashi, 2011). Included in this high-risk category are individuals who have three or more first-degree relatives with a diagnosis of pancreatic cancer and anyone diagnosed with FAMMM, PJS, or hereditary pancreatitis (Brand et al., 2007; Syngal et al., 2015). In certain cases, some patients may not have a tenfold risk, but increasing screening is warranted. Patients who fall into this category include those who have a cancer syndrome that puts them at an increased risk and one family member who is either a first- or second-degree relative who has had pancreatic cancer or an individual who has two first-degree relatives who have had pancreatic cancer (Canto et al., 2013; Matsubayashi, 2011). According to expert opinion at the American College of Gastroenterology, individuals who are at an increased risk of pancreatic cancer due to pathogenic variants in *BRCA1, BRCA2, PALB2, ATM, MLH1,* or *MSH2* should only undergo increased screening if

they have a first- or second-degree relative who have or had pancreatic cancer (Syngal et al., 2015). Individuals should also receive increased screening when they have risk factors of IPMN identified, pancreatic cysts, diabetes mellitus, chronic pancreatitis as well as a hereditary component (Matsubayashi, 2011).

New screening methods are being investigated that allow for better imaging, which can aid in identifying cancers earlier so treatment can take place (Tewari, 2015).

2.3.2 Treatment

Treatment can be difficult due to diagnoses that occur at later stages of disease. However, surgical treatment is available when diagnosed early. The Whipple procedure is a surgery that can extend life and provide a potential cure (Lewis et al., 2009). A Whipple procedure involves the resection of part of the pancreas along with other surrounding organs in addition to reconstruction of the bowel (Schwab, 2011). A Whipple procedure is best suited for patients with localized cancer; however, it is possible that there could be unidentified metastasis to other organs (Schwab, 2011). Lewis et al (2009) discuss the importance of early detection prior to metastatic disease so this procedure can be done. While the surgery is complicated, many patients who have received a Whipple procedure report a high quality of life after surgery (Lewis et al., 2009). It is currently debated as to what the best approach of resection is; whether to remove all lesions identified that are precancerous, or to remove only certain areas should be removed that have cystic or nodular lesions (Matsubayashi, 2011). Although surgery can be done to remove the cancer, about 20% of patients die within a year after the procedure because of recurrence (Tewari, 2015).

There is still debate surrounding the best treatment for patients who have locally advanced cancer; however, current standards are radiation and chemotherapy together (Schwab, 2011). Some studies have shown, however, that pancreatic cancer can be resistant to chemotherapy treatments (Tewari, 2015). Chemotherapy along with support care is the standard for patients who have metastatic disease (Schwab, 2011).

2.4 PSYCHOSOCIAL CONSIDERATIONS

People in the general public sometimes believe that the majority of cancers are inherited; however, only about 5-10% of cancer cases are due to a familial pathogenic variant. Without this understanding, some people may believe that their risks are much higher than that of the general population when they have a family member who has had cancer (Epstein et al., 1997). Some individuals may have an increased perception of risk because they show similarities to an affected family member (Howell et al., 2013), and it can be difficult to correct this misinformation.

A family history of cancer may lead to anxiety over one's personal risk of developing cancer. Studies have found that this increased anxiety can lead women to perform self-breast exams more often than necessary when there is a family history of breast cancer (Antill et al., 2006; Epstein et al., 1997). Studies have shown with regard to hereditary breast and ovarian cancer families, while individuals may understand the risks related to possessing a pathogenic variant, family history and experience with these cancers can overpower the risk data that are provided to them (Gopie et al., 2012; Underhill et al., 2012). Lovegrove et al. (2000) surveyed women in the United Kingdom who have a family history of breast cancer to assess their risk

perceptions. Women who were at an increased risk due to family history were found to overestimate their risks for developing breast cancer and the younger the women, the higher the risk perception they had (Lovegrove et al., 2000). Psychological distress may increase when an individual believes he or she has a high risk of developing cancer as well has having a negative perception of possible diagnosis outcomes (Gopie et al., 2012; Vaidya et al., 2015). This increased anxiety has been shown to decrease after undergoing genetic counseling, when personalized risks can be provided to patients (Daly et al., 2006; Vaidya et al., 2015).

In contrast, some individuals who are considered high-risk due to family history may not perceive themselves as high-risk until they develop cancer or have signs of cancer (Salant et al., 2006). Having this disconnected perception of personal risk can lead individuals to not seek out care at a high-risk clinic (Salant et al., 2006). The age at which another family member is diagnosed, or the number of family members diagnosed with cancer may influence the up-take of increased screening (Bujanda et al., 2007).

There may be similarities between individuals with pancreatic cancer as well as individuals with other high-risk cancer such as breast and colon cancers because of the increased screening they undergo and fear they may feel. Some patients within the high-risk breast cancer community experience higher levels of distress when imaging techniques identify abnormalities (Underhill et al., 2012). Families who have cancer syndromes that put them at an increased risk for rare cancers have been shown to have a higher psychological burden than families who are at risk for more common forms of cancer (Gopie et al., 2012). The screening process itself and anticipation of results have been found to increase stress levels for patients with familial breast and colorectal cancers (Maheu et al., 2010). After undergoing screening and receiving normal

test results, stress levels decrease in patients who at an increased risk for breast and colorectal cancers (Maheu et al., 2010).

Not much research has been completed with regards to individuals' experiences of being at an increased risk for pancreatic cancer. Previous research related to hereditary breast and ovarian cancer as well as hereditary colon cancer has shown that there can be a psychosocial impact due to many factors such as cancer risk perceptions and worry, as well as wanting to control the risk that one may develop cancer (Underhill et al., 2015). Family members of individuals with a diagnosis of FAMMM have been found to overestimate their risk of having the *CDKN2A* pathogenic variant even after receiving genetic counseling (Lynch et al., 2000). Two main reasons for individuals to seek out genetic testing when there is a known familial mutation in *CDKN2A* are to know if future generations need to undergo testing, and to help in determining the need for increased screening (Lynch et al., 2000).

2.5 DOCTOR-PATIENT RELATIONSHIP

Historically, a physician's word was taken at face value, and little attention was given to the thoughts and feelings of the patient. More recently, health care has developed a more patient-centered approach whereby patients are expected to become more engaged in their care by sharing their motivations for seeking medical attention, explaining their symptoms, and letting their expectations be known (Bensing et al., 2013). Not only is it important for doctors and patients to maintain open communication through questions and answers, but it is also important for underlying patient emotions to be acknowledged and addressed (Bensing et al., 2013). Patients are more likely to comply with treatment, report a higher level of satisfaction, and are

less likely to search for another doctor when they have established a positive relationship with their current doctor (Baron-Epel et al., 2001; Yacavone et al., 2001).

2.5.1 Patient Satisfaction

Understanding and evaluating which elements of medical care patients consider important can help create environments in which patients feel that they are receiving optimal care. Patient satisfaction is a subjective measure based on the patient's perceptions and personal expectations (Ware et al., 1983). Satisfaction with a health care setting can be determined by ascertaining whether the patient's expectations of care were met (Baron-Epel et al., 2001). When patients do not feel as though their needs have been met when compared to what their expectation of the care was, they generally experience lower levels of satisfaction (Baron-Epel et al., 2001). High levels of patient satisfaction have been shown to increase patient compliance with treatment plans, which in turn tends to lead to better health outcomes (Firth et al., 2011). There are eight categories on which patient satisfaction is rated: interpersonal care or bedside manner; technical quality of care; accessibility/convenience related to appointment availability and wait times; finances (particularly those related to insurance coverage), efficacy/outcomes; continuity of care; the physical environment of the facility in which the care is received; and availability (Andaleeb, 2001; Ware et al., 1983; Yacavone et al., 2001). Andaleeb (2001) identifies the importance of friendly and helpful support staff to help prepare patients for a positive experience.

Providing medical care to a patient does not simply mean completing a procedure, administering medicine, or even providing a cure. It also includes moving beyond the physical ailment and seeing a patient more holistically, as an individual who is going through a challenging experience and how such an experience can affect other aspects of his or her life (de

Boer et al., 2013). It is also important for the provider to recognize how previous experiences in his or her life may help in making a connection with the patient so they can work in a collaborative manner (de Boer et al., 2013).

2.6 HIGH-RISK CANCER CLINICS

Individuals with a genetic predisposition to develop cancer may experience increased levels of distress, frustration, and anxiety compared to the general population (Firth et al., 2011; Pichert et al., 2010). They are faced with numerous decisions regarding management including risk-reducing surgeries, chemopreventative therapy, and increased screening (Firth et al., 2011). In addition to a complex array of emotions and potentially life-altering decisions, individuals who are the first in their family to be identified as a pathogenic variant carrier have the added task of disclosing this information to other family members who are also at risk of carrying the pathogenic variant (Firth et al., 2011). In order to make informed decisions regarding their care, individuals need to be provided with support and information about their increased risk as well as the benefits and limitations of each treatment option. High-risk cancer clinics were developed as a clinical service where individuals could receive this comprehensive care. The first multidisciplinary high-risk breast cancer clinic was conceptualized and established in the United Kingdom in 2002, and since then various clinics have adopted this care model (Bancroft et al., 2010). The introduction of high-risk clinics has resulted in better management of high-risk patients (Pichert et al., 2010).

The purpose of having a high-risk cancer clinic is to allow for a multidisciplinary approach to individualized patient care (Bancroft et al., 2010; Gomella et al., 2010). The need for

high-risk clinics is increasing as more individuals seek out predictive genetic testing (Bancroft et al., 2010). Regular contact between clinic staff and patients allows for dissemination of the most current information and provision of psychosocial support when needed (Ardern-Jones & Eeles, 2004; Bancroft et al., 2010). A high-risk clinic allows for a known place where patients can return to plan for next steps in care or to gain more knowledge about available management procedures (Bancroft et al., 2010; Engel et al., 2012; Firth et al., 2011; Gomella et al., 2010). Different high-risk clinics are composed of a variety of health-care professionals including, but not limited to medical geneticists, oncologists, surgical oncologists, genetic counselors, nutritionists, social workers, physiotherapists, psychologists, and psychiatrists (Bancroft et al., 2010; Engel et al., 2012; Firth et al., 2011; Gomella et al., 2010). Having all relevant care providers in the same place allows for consistency in information being provided and all questions to be answered at the same time (Firth et al., 2011). Additionally, high-risk clinics serve as an information source for genetic risks, thus lowering the chance of information to be lost while speaking to different providers (Bancroft et al., 2010). It has been found that individuals who are at an increased risk of developing breast cancer and who are followed in a high-risk clinic setting have a higher likelihood of early cancer detection (Vaidya et al., 2015). Furthermore, disease incidence has also decreased for high-risk populations because of risk-reducing surgeries (Gomella et al., 2010; Vaidya et al., 2015). In addition to the comprehensive care that is provided at high-risk clinics, patients generally have more access to clinical trials usually due to the fact that the majority of high-risk clinics are associated with an academic institution (Gomella et al., 2010).

Following the multidisciplinary approach, some high-risk clinics offer patients the opportunity to speak with a psychologist (Firth et al., 2011). This provides patients a safe place

to speak about a loved one whom they have lost, possibly due to the same cancer, as well as the opportunity to address the changes one might experience emotionally should they decide to undergo a risk-reducing surgery like a double mastectomy in the case of *BRCA* (Firth et al., 2011). Some clinics have initiated peer support networks for patients facing the same challenges, for example, preventative surgery (Pichert et al., 2010).

High-risk clinics face several challenges (Bancroft et al., 2010; Daly et al., 2010; Engel et al., 2012). For example, dissemination of updated information and protocols to health care professionals and high-risk families has been reported to be a challenge for clinics, highlighting the need for patient follow-up (Bancroft et al., 2010; Daly et al., 2010; Engel et al., 2012). Further, with the high volume of patients who are seen in high-risk clinics it may take longer for patients and other providers to receive follow-up letters to appointments (Firth et al., 2011). Referral of appropriate patients to high-risk cancer clinics can also prove to be a challenge. This can be due to primary providers not being aware of the clinic or what patients are appropriate to refer. In some cases, appropriate patients are referred but they do not understand why they would need to attend a high-risk clinic (Daly et al., 2006; Engel et al., 2012; Vaidya et al., 2015). While a number of academic hospitals have high-risk clinics, community hospitals are having a difficult time getting programs established due to a shortage of trained cancer and genetics experts who are required for the success of a high-risk program (Daly et al., 2006).

2.7 HIGH-RISK PANCREAS CLINIC

One high-risk cancer facility that is available is the High-Risk Pancreas Clinic, located at Shadyside Hospital in Pittsburgh, Pennsylvania, and part of the University of Pittsburgh Medical

Center (UPMC) health system. Under the direction of Randall Brand, MD, the mandate of the clinic is to provide information to individuals regarding their risk of getting pancreatic cancer and options for surveillance and prevention (Silver, 2012).

Patients may attend the clinic based on referrals from a number of individuals including primary care physicians, oncologists, genetic counselors, family members, or self-referral (Silver, 2012). At the clinic, a genetic counselor from the team gathers information about the patient's medical and family history, provides counseling about hereditary pancreatic cancer and offers genetic testing if indicated (Silver, 2012). The flow of the session shows a number of similarities to a general cancer genetic counseling session (Silver, 2012) but with a focus on pancreatic cancer and related syndromes.

After completing counseling, Dr. Brand provides information regarding methods of preventing pancreatic cancer and current screening that is available (Silver, 2012). The information provided to the patient about screening includes a description of the screening appointment, how the screening methods work, and the benefits and limitations of screening (Silver, 2012). After receiving this information, patients can decide if they would like to begin the screening process (Silver, 2012). Patients who are eligible to participate in the PAGER Study are invited to enroll; interested individuals are enrolled during their clinic visit.

Research has been conducted evaluating patient experiences in high-risk cancer centers. This research has typically evaluated more common cancer clinics such as breast or colon cancer. This study aims to add to the limited data surrounding patients at a high-risk pancreatic clinic to improve patient care and to assess whether patients feel satisfied with the care they are receiving.

3.0 SPECIFIC AIMS OF THE STUDY

Aim 1: Study participants' experiences of having a family history of pancreatic cancer.

Aim 2: Investigate participants' experience with the UPMC High-Risk Pancreas Clinic.

4.0 METHODS

4.1 FOCUS GROUPS

The focus group was conceptualized by Sheila Solomon, MS, LCGC and was approved by the University of Pittsburgh Institutional Review Board (IRB) (PRO12070378). The IRB approval letter is included in appendix A. Focus groups were facilitated by Dr. Martha Terry, a qualitative researcher with extensive expertise in conducting focus groups. There were a total of 28 participants who agreed to participate in the focus groups. Three focus groups were conducted over two evenings. On the first night, patients of the clinic and caregivers were separated into two groups see to explore whether a more homogenous group composition would generate a different type of conversation. A second facilitator, Teagen O'Malley facilitated the caregiver group. The guides for the patient and caregiver focus groups are in appendices B and C, respectively. A medical fellow at the high-risk clinic sat in and took notes during the patient focus group on the first night. Sheila Solomon, the genetic counselor at the high-risk clinic took notes during the caregiver focus group the first night and the focus group that included both patients and caregivers on the second night. The author's role was to analyze the data from the focus groups.

4.2 PARTICIPANTS

For the purpose of this paper, individuals who attend the High-Risk Pancreas Clinic for increased screening due to their increased risk for pancreatic cancer are referred to as ‘patients.’ At the time of the focus groups, no patient had been diagnosed with pancreatic cancer. The participants who accompanied patients are referred to as ‘caregivers.’ Caregivers encompassed mainly spouses of patients; however, there were some adult children of patients and one niece of a patient. The children and niece acknowledged that the clinic was available to them, but for various reasons they had yet to attend.

4.2.1 Participant Recruitment

Participants were recruited from the larger population in the PAGER Study conducted through the high-risk pancreatic clinic in Pittsburgh, Pennsylvania. PAGER enrolls patients of the high-risk pancreatic clinic to understand what causes pancreatic cancer through environmental and gene interactions (“Pancreas & Biliary Center,” 2014).

Both patients of the clinic and caregivers were invited through a mailed invitation to attend the focus groups. There were two dates that participants could choose to attend. When participants responded saying they would attend, they were consented to take part in the focus groups. Additionally, prior to starting the focus group another consent was read out loud by the facilitator whereby choosing to stay at the table and be apart of the discussion participants provided their consent to be audiotaped and have their comments added to the research data.

4.3 TRANSCRIPTION

A total of three focus groups were held, one of which was partially transcribed live by the high-risk clinic's medical fellow. The remainders of the focus groups were transcribed by the author into Microsoft Word verbatim. The grammar, and any form of filler language were preserved in the transcripts of both the facilitators and participants.

4.4 THEMATIC ANAYLSIS

4.4.1 Familiarization with data

The author became familiar with the data during the transcription process and by reading the completed transcripts once more prior to coding. The data of the transcripts were the driving force of the research. The analysis conducted was inductive in nature, as described by Braun and Clarke (2006). Inductive analysis allows for the data to drive the analysis, where themes are identified based on the collected data (Braun & Clarke, 2006).

4.4.2 Generating initial codes

Coding is the process of labeling text and starting to link data together (Richards & Morse, 2007b). The author coded the transcripts by reading each statement and creating a code for it and defining the code. The codes were then compiled in a Microsoft Excel spreadsheet before categorizing and arranging them into themes. The codebook used to organize the codes is

attached in appendix D. Included in the codebook are the codes, where each transcript the codes can be found, the definition of each code, and the subtheme and/or theme each code belongs to. Due to formatting constraints, the quotes of each code were removed. Due to the nature of focus groups, some exchanges between participants were grouped together to preserve context.

There are three different types of coding; descriptive, topic, and analytic. Richards and Morse (2007) describe descriptive coding as information that is known data. In the context of this research, information regarding whether a participant is affected, at an increased risk, or a caregiver are descriptive items. Topic coding is separating all of the data into different topics (Richards & Morse, 2007b). This form of coding was used throughout to help categorize participants' experiences at the clinic and identify what additional items they want from the clinic. The final type of coding is analytic. Analytic coding is a more in-depth look at the data that allows for identifying new themes or concepts that may not have been previously noted (Richards & Morse, 2007b). Analytic coding was used to help characterize any subtle themes within the data that may not have been recognized from prior coding techniques.

During the coding process there was examination of the literature and the original transcripts to decide on the best code for each statement. A codebook was made with definitions of each code within an Excel spreadsheet. Similar codes that related to a similar concept were grouped together. All statements with the same code were then color-coordinated and grouped together.

4.4.3 Identifying and characterizing themes

A theme, as defined by Richards and Morse (2007b), "runs right through data and is not necessarily confined to specific segments of text" (page 143). Themes were created by reviewing

all of the codes and deciding what central idea tied certain codes together. Some codes were grouped into subthemes prior to theme categorization. Subthemes were constructed when codes were closely linked to one another, but were not broad enough to be their own theme, i.e. they still fit into an overarching theme. The theme making process was fluid in that codes were arranged and rearranged to identify the most appropriate themes for analysis. Through this process most codes were grouped together into themes but some codes were left out. The analysis yielded five main themes. Some codes were not included in the themes because some were generated from conversations that were off topic of the focus groups or because they were not conceptually related to a theme. The main five themes are described in the results section.

4.4.4 Analysis Example

The following is an example of how codes were identified from transcript passages. A single comment may be coded with one or more codes. As stated previously, some codes were sorted into subthemes prior to being categorized into a major theme. The examples below are from three different participants during the focus groups and exemplify a number of the different themes identified in the research.

Table 1. Example of focus group analysis

Quotes	Codes	Subtheme	Themes
X: "It seems to be doing everything right. It seems that they have their hand on it. They are involved in this society and they seen very aware. My wife was concerned, not concerned, interested in the news clip we saw a couple of months ago the boy that invented the blood test and I'm wondering if that has progressed any further."	Satisfaction		Attributes of the clinic staff
	Info seeking – new research		Goals for the clinic
Y: "It makes me nervous to think..."	Fear	Feelings of being at risk	Fear of developing cancer
Z: "It gives me a peace of mind to know that they are following him so if something turns up then we are in a position early on to make a decision of what should and shouldn't be done."	Early detection	Providing hope	Attributes of clinic staff

5.0 RESULTS

There were a number of topics discussed during the focus groups, through the thematic analysis identified five main themes that will be described in this section.

5.1 THEME 1: ATTRIBUTES OF CLINIC STAFF

The participants in the focus groups described a number of positive aspects of the High-Risk Pancreatic Clinic at UPMC Shadyside. Participants spoke highly of the friendly clinic staff and the exceptional care they received from Dr. Brand and the genetic counselor, Sheila Solomon. Outlined below are the strengths of the clinic that were identified by the study's participants.

5.1.1 Attention to Patients

One aspect many participants brought up was the length of the appointments, which allowed for a thorough explanation of the risks, inheritance, and possible screenings and treatments of the disease. One participant spoke about the attention the team provided to her mother when she was at her appointment:

> When you're with them, I feel like my mother is their most important patient that they have. I do. And I know that she's not because they are all people that are all equally important, but that is the feeling that you get and that is a great

> feeling because in my opinion I think that a lot of that has been lost medicine. I do. And I think that is very important.

Similar comments were made by other participants who appreciated the time the team took to get to know them. As one participant commented:

> I echo what you said, it's like you're the only person they're talking to. I've never been to a doctor anywhere that made me feel like that. He had to have had a whole morning full of patients, but they schedule well because they give you your hour or whatever that is booked.

The longer clinic appointments appeared to allow participants to gain a better understanding of the benefits and limitations of screening, voice their concerns, and have their questions answered. One participant discussed how Dr. Brand's approach allowed her to recognize the importance of a colonoscopy:

> He has wonderful bedside manner. I certainly did not want to do it at all. And he was able to convince me to do it the first time. And he was able to convince me this year to do a colonoscopy. I have no idea how he got me to do that. But he has an easy way about him that's kind of very convincing without being scary or anything like that.

5.1.2 Considerate of Patient's Opinions

When faced with management options, participants appreciated being involved in the decision making process. A participant described his hesitancy when Dr. Brand brought up the idea of removing his whole pancreas via a Whipple procedure. The participant stated that he did not want to undergo surgery unless it was absolutely necessary. Dr. Brand listened to the participant's concerns and did not push him into the surgery and they agreed that increased screening would be done.

> Dr. Brand kind of scared me last year when I came to see him. He come and says 'You know, now Al, we would like to remove your pancreas completely.'

> And it's like (laughs). What?! So you know… And I ask him questions; you know, how about special diet? ...Definitely, I would be on insulin. The thing is, he said. You know you have to talk about to Dr. Moser about all that. Just then he had a phone call. It was Dr. Moser. So he comes back and he says you know I was just talking to Dr. Moser. They were real close, you know. They work together. He come back and says you, Dr. Moser thinks we gotta just keep sitting like that. I gotta get an MRI and go endoscopic every six months I get one or the other. That sounds better to me than to remove it.

Thus, this participant did not have to undergo a life-changing procedure because Dr. Brand listened to the participant and corresponded with the participant's surgical oncologist to develop a plan with which the patient felt comfortable.

5.1.3 Clinic Presence

Some focus group participants admitted that they are not the most committed patients. They acknowledged that they should be attending the clinic on a more regular basis. These participants have found that no matter how long they have been away from the clinic, the team is always there for them and their care.

> But then… but they are there. They are definitely a presence. Once you get associated with them, it seems that they are available for you. They can only go so far for making you come in by making an appointment.

> But, even though I haven't been very good at responding back to them, they haven't forgotten me. Don't give up. Even if we don't respond, don't give up. Even if we don't call back.

One participant remarked that no matter what, "You have to have some place to turn." These remarks appear to note a feeling of comfort from the study participants. They suggest that when they are ready to be seen at the clinic, they will still have that opportunity.

5.1.4 Empowered to Engage Family

In some cases, individuals learn during their clinic appointment that there is a genetic cause for an increased risk of developing pancreatic cancer in their family. This information is important for patients to understand so they can explain the risks to family members who may also be at risk of carrying a pathogenic variant. This task of relaying information to other family members can be daunting to some individuals, but as one participant pointed out, after speaking to Dr. Brand and the clinic team, he felt empowered to go home and talk to his family, so they too were more informed and could make relevant health care decisions.

> It certainly encouraged me to go home and convince my family members and explain what they needed to do.

5.1.5 Providing Hope

Participants acknowledged that pancreatic cancer can be devastating due to the generally late stage diagnosis and the lack of proven screening modalities. However, they find that attending the high-risk clinic gives them hope that early detection will lead to a better chance of survival. One participant remarked:

> …and that's when he referred me to Dr. Brand. And it was then...well maybe that's a string to hold on to. You know that... Maybe my fate will be better than my brother and my sister. And then I think I have a chance.

A number of participants expressed similar thoughts about the possibility of early detection, which could lead to early treatment. One participant stated, "If we know early enough, we can operate."

Another participant shared a similar sentiment, further adding her feelings of relief that her husband is monitored by the clinic so that changes in the pancreas can be identified early,

> Knowing that [husband] is being followed to me is a great relief because we are not going to suddenly discover that he doesn't feel well today and then tomorrow find out that he has advanced pancreatic cancer because we will know along the way before it gets serious before there are any symptoms. Which, I think, is why pancreatic cancer is so deadly it's because you don't get symptoms until things are well along the way. So I find it a big relief.

Although study participants acknowledged that the increased screening may not have high detection rates, they still wanted to pursue it, therefore providing themselves with some relief and hope.

5.1.6 Staff Expertise

Patients want to feel that they are being followed by a competent doctor; the participants in this study are no different. Participants spoke about the reputation of Dr. Brand and his training under Dr. Lynch, who characterized Lynch syndrome, and the clinic and how they feel fortunate to have this expertise available to them.

> …there are other places in the United States as good as Hillman Cancer Center, but there is none any better. Don't go anywhere else, just stay home in Pittsburgh and take advantage of the facilities that are there.

Not only did the participants' comments suggest that they recognize that they are receiving care from experts in their respective fields, but they also appreciated Dr. Brand and his team for how personable they are and the compassionate care they show their patients.

5.2 THEME 2: POTENTIAL BARRIERS

Barriers emerged in the focus group discussion and have the potential to limit individuals from attending the high-risk clinic. The most significant barrier that participants spoke about was the cost of the procedures and insurance not fully covering the cost, resulting in high co-pays. One participant explains her difficult predicament with regards to insurance not covering the cost of her testing:

> The other concern I have is should I be tested again? It has been over a year since I was tested, but I have a deductible in my insurance. It's one thousand two hundred and fifty dollars, it was three thousand dollars until I retired in June of this year, now it's one thousand two hundred and fifty dollars and I'm paying out my own insurance now. I do not have that one thousand two hundred and fifty dollars to get this test and there should be some kind of grant or there should be something established for people who are at high risk, but I can't come because I can't afford it so that's another point I would like to make. I just don't know how I'm going to afford this and yet how can I not afford it cause my two brothers both died from it.

Due to competing insurance companies, some participants said their insurance was no longer accepted at the clinic because the hospital was not in the same network as their insurance. This led to frustrations because they felt that seeing Dr. Brand and his team would provide them with the best care:

> But once again, if you don't have the right health insurance, with this health insurance battle that's going on, you can get into a lot of trouble and not be allowed to come here. That shouldn't be. If this is a good place and you have a problem, you should be allowed to come here. That needs to be settled also.

The cost of genetic testing can dissuade some individuals from pursuing it. Even though genetic testing can help determine if increased screening is needed, insurance companies do not always cover the testing:

> They said it was three thousand dollars, I'm a senior, I don't have three thousand dollars so I couldn't do that part.

Participants suggested that if financial considerations were not a factor, then additional family members could attend the clinic to receive information, pursue genetic testing and/or further screening measures. One participant spoke about the possibility that grant money secured by the clinic would allow his brother to seek testing:

> They just said that they got grant money for people that their insurance would not cover the genetic testing. So my brother, so he is one of my brothers who is willing to get tested now. I am hoping the other two would come around and get tested.

The participants in this study did not identify any other aspects that they perceived to be barriers to receiving additional screening, with the exception of not being motivated to attend the clinic, which is discussed in more detail within the family theme.

5.3 THEME 3: FEAR OF DEVELOPING CANCER

Some participants expressed that the fear they feel, or the fear a family member feels keeps them from seeking care at the clinic. As one participant stated, "I have not yet become a patient of Dr. Brand's, because I am scared to death."

Another participant shared how her sister-in-law's fear has also led her to avoid attending clinic:

> We are trying to get his sister to come in but she's afraid, like you, and she puts it off.

Some participants made comments that acknowledged the fear of the unknown and fear of receiving a devastating diagnosis in the future. One participant stated, "Yeah, it's like a time bomb waiting to go off."

Another participant, who has a *BRCA* pathogenic variant spoke about her child and how she wants this child to undergo genetic testing once she is old enough, but at the same time she is fearful of the potential outcome.

While some participants verbalized their fear of developing pancreatic cancer, they also expressed that they did not let this increased risk rule their lives. One participant remarked:

> I don't like to be preoccupied with the unknown if you can't do anything about it. Not that you want to forget about it, I don't want to get too concerned about it.

One participant found filling out a questionnaire after being seen in clinic to be helpful in reflecting upon how she felt being followed in the clinic and undergoing additional screening. She discussed the fear experienced with the screening tests knowing there is the possibility of receiving a cancer diagnosis:

> I responded back and I was glad to do that because it stops and makes you think as you are going through all this emotionally… How did you feel before the testing? How did you feel after? Afterwards were you more fearful of getting pancreatic cancer, is doing all these tests make you more fearful? It was a lot to deal with the emotional aspect of it. That's something I think they don't address always how frightening it is for everybody (mumbles) there's some chance that anyone can get it. I think that is important. I don't think many people would say it, but I think yes because it is that emotional aspect with how frightening it really is. Does all this make it worse, doing all these screenings, did you find it helpful, do you think it really means anything? Because they did this they are going to find something, and if they do, is that going to mean..? If they find something early, can they do anything about it?

Fear was the feeling most often discussed by participants. They spoke about how pancreatic cancer can go undetected, and people might not know until it is too late for effective

treatment. Although they shared being fearful, they also acknowledged that they try to not let fear dictate their lives; they try to be conscious of their increased risk but not allow it to consume them.

5.4 THEME 4: FAMILY

Family influences can serve as a motivating factor to seek genetic testing or screening tests. For example, some may seek care once they recognize that they are at an increased risk due to the presence of a family history. Some may feel compelled to get care because family members pressure them to do so.

5.4.1 Family Support

One participant shared a story about her family coming together to discuss with their mom the idea of having her pancreas surgically removed:

> But we discussed as a family before she had the surgery. We said, 'Mom, here's the bottom line; you can live with diabetes, even being a brittle diabetic, you can live. You can't live with pancreatic cancer.' So it really was a no brainer because, you know.

The same participant went on to discuss not having attended the clinic yet, but recognizing the importance of doing so for her family; "But I have to. I promised my family that I would."

Another participant, who is a caregiver, shared his insight on his wife attending clinic and the support he wants to provide her:

> I support her. You know she wanted to come here, I said let's do it. I'm willing to do whatever it takes to help her follow through with it, whatever has to be done.

If patients are feeling overwhelmed with everything they are experiencing with their health, having the support of a loved one can be a vital coping resource.

5.4.2 Frustration

While family can provide great support, they can also serve as a source of frustration. Some participants expressed their frustration with various family members because they were not interested in attending the clinic, getting genetic testing or undergoing increased screening. One participant shared the following:

> For years, for the past three years I have been telling her and she has been no… no…does not wanna know… does not wanna know… does not wanna know…had no interest. And her husband passed away from cancer last week.

One participant discussed her uncle who would not follow his doctor's recommendations, and the frustration she felt:

> There were these pills he was supposed to take and they were really expensive, he could afford to buy them, just buy them. For Pete's sake, if they aren't covered, buy them (emphasis). It was just things like that that were frustrating when I saw him go through it. I can't say he didn't take it seriously… I think with my aunt that is here, I think she tried to encourage him, but she wasn't firm enough with him. Okay, this is what you have to do, this is what you have to do, this is what you have to do. She wasn't firm or strong enough. Like she kind of took a back seat, like well, he has to make this decision, he couldn't really.

5.4.3 Loss

The death of a family member can be a painful experience and grief was described by participants. One participant shared:

> You are almost lost when you lose a person. It's like 'Oh my God! I can't believe this happened.'

Some participants shared that the loss of a family member served as motivation to attend the clinic and begin increasing screening. One participant discussed losing two siblings:

> And I asker her doctor, what can I do ...I mean ...One... Two...Am I going to be the third? So what do I do?

These results suggest that the participants in this study care for their family members and want them to be healthy, but sometimes a family member's unwillingness to attend clinic and differences in approaches to health care can lead to frustrations within a family.

5.5 THEME 5: GOALS FOR THE CLINIC

In general, participants felt that the clinic is doing a good job in providing care. Their comments suggested that they appreciate receiving the PEARL (Pancreas Education and Research Letter), which is sent out quarterly and has information about ongoing research in the pancreatic cancer community in general as well as current research conducted at the clinic. Areas the participants identified that could always be enhanced within the pancreatic cancer community include continual research to improve screening to decrease mortality rates. Specifically for the clinic, some participants were looking for more help in engaging family members, and some logistical aspects of the clinic. These areas are discussed below.

5.5.1 Information Seeking

The participants indicated that they are looking for as much information as possible in regards to lifestyle changes that they can implement to help decrease their risk of getting pancreatic cancer. One participant remarked: “And I ask him [Dr. Brand] questions; you know, how about special diet?”

Another participant commented that individuals do not know much about the relationship between diet and the pancreas. The participants seemed informed on the relationship between increased risk of developing pancreatic cancer and smoking. As the following comments suggest, a number of participants wanted to receive updates about what the clinic is finding from the PAGER study and for research to focus on better screening methods that are cheaper, faster, and less invasive.

> What has the group learned in the last year or so? Yeah, are they moving forward, are they getting new improvements from it? I know they are working hard on it, it seems like.
>
> Find a better easier testing that can be done without so much cost and easier. As I said, you could go to your GP and get this blood work done. And my God... that would be it. And it is early detection.
>
> Keep researching!
>
> They need a faster, slicker, cheaper screening.

5.5.2 How to Engage Family Members

Participants spoke about the care they received from the clinic and their hope to involve other family members. Some participants discussed feeling empowered to go home and talk to their

families about genetic testing or participating in increased screening. Other participants spoke about how they needed help in finding information about pancreatic cancer for their family members and motivating interest in them to attend the high-risk clinic. One participant spoke about her desire to have lectures or websites that could be shared with families to facilitate access to medical information:

> I would like to get the children, our nieces and nephews of the dead brothers to be a little more involved… Any lectures that are out there on it.

One participant thought that appealing to altruism may be the best way to provide information and involve family members in the clinic and PAGER study:

> And I wonder if what you said about the follow-up that you got at home, perhaps if that had been addressed more in the session with my cousin who is panicked, who won't do it, who is most likely obese, early breast cancer, diabetic. She's our high-risk person and she won't do anything about it. And it's like maybe you need a little bit more information impressing upon them, and maybe not looking at them, but looking at what they can provide for others.

5.5.3 Logistics

A more practical concern that the participants had was the lack of clinic staff available to perform blood draws needed for research studies and genetic testing. Two participants shared their thoughts, one expressing that it would be inconvenient to travel into Pittsburgh to only have a blood draw completed.

> So the phlebotomist has gone home I would have to come all the way back from Mt. Lebanon, and that was a little bit of a problem. I thought maybe they should have someone there who they could call to take my blood. That is my only complaint.

> So that would be something they need to improve upon; making sure there is someone on staff when they need your blood who can take it and who knows how to do it.

One participant suggested that if there were not already a grant system in place for those who are unable to afford the screening, they would like to see one initiated so all those who are at risk can be provided with the care they need if they are hindered by cost.

Overall, participants were pleased with the care they or their loved one were receiving at the clinic. They expressed a desire to receive additional information pertaining to research initiatives, an easier and more accurate screening modality, and more accessible phlebotomy services.

5.6 CONNECTION OF THEMES

There are conceptual elements of the themes that can be linked to one another. For example, while some participants described fear as a barrier for why they had yet to attend the clinic themselves, other participants noted that they feel frustrated because some of their loved ones will not speak to Dr. Brand because they are incapacitated by fear. This shows a connection between the family theme and potential barriers theme. Therefore, there are not discrete boundaries between the themes and there are aspects of the themes that are related to one another.

6.0 DISCUSSION

The goals of this study were to explore participants' experiences of having a family history of pancreatic cancer, as well as to investigate participants' experiences with the High-Risk Pancreatic Clinic at UPMC Shadyside. Although not much research has examined patient experience in a high-risk pancreatic clinic, there is research that has studied patient experience in high-risk breast and colon cancer clinics, to which these current results can be compared. Additionally, research evaluating general practitioners and the qualities patients seek out, can be extrapolated to the current study.

Similarly, the feelings surrounding having an increased risk for developing pancreatic cancer have not been explored thoroughly, but have been studied for breast and colon cancer. Again, parallels to the current study and the previous studies surrounding breast and colon cancer can be drawn.

We used focus groups to allow patients to retrospectively reflect upon their experiences at the High-Risk Pancreatic Clinic at UPMC Shadyside Hospital and analyzed the data from the focus groups to better understand patients' perceptions of their experiences in a high-risk pancreatic cancer clinic.

6.1 THEME 1: ATTRIBUTES OF CLINIC STAFF

The participants identified several positive attributes of the High-Risk Pancreatic Clinic including the attention paid to patients, taking patients' opinions into consideration, helping patients feel empowered to talk to their family, being available to patients and providing them with hope, and the overall expertise of the staff. These types of attributes have been described in other studies (Andaleeb, 2001; Bensing et al., 2013; Carney et al., 2006; Crooks et al., 2012; Kaiser et al., 2011; Lewis et al., 2009; Schildmann et al., 2013; Thorne et al., 2013). They emphasize the importance of cultivating a strong doctor-patient relationship and describe the characteristics of the relationship. The characteristics that foster a positive doctor-patient relationship include open communication, trust in the doctor, feelings of empowerment, and the doctor providing hope for the patient (Andaleeb, 2001; Bensing et al., 2013; Carney et al., 2006; Crooks et al., 2012; Kaiser et al., 2011; Lewis et al., 2009; Schildmann et al., 2013; Thorne et al., 2013). The participants expressed their satisfaction with the strong doctor-patient relationship that is present at the high-risk clinic, and were confident that they will be receiving the best care possible.

6.1.1 Attention to Patients

A major area of satisfaction with the clinic that the participants acknowledged was their interactions with Dr. Brand and other clinic staff. They were pleased with Dr. Brand's bedside manner, which made them feel comfortable and allowed them to put their trust in him. The importance of a good bedside manner has been identified in other research (Crooks et al., 2012; Thorne et al., 2013), where having a good bedside manner and respecting the patient and his/her

opinions led to more open communication between the doctor and patient, which in turn, led to a higher level of treatment compliance.

The comments the participants in this research made about appreciating having time to ask questions and express concerns highlights the importance of effective doctor-patient communication. When doctors take time with patients, it allows patients to gain a better understanding of what is available to them, whether it is predictive genetic testing, screening for early detection, or possible preventative surgery. By listening to the participants' concerns, Dr. Brand shows that he values listening to his patients' thoughts and opinions as well as respects them. The work by Bensing et al. (2013) suggests that effective communication starts to occur when patients are given the opportunity to ask questions and use their own words as oppose to medical terminology to communicate about their health.

The participants acknowledged the trust that they have placed in Dr. Brand and the screening tests that he recommends. Kaiser et al. (2011) found that many cancer patients believe the trust they have in their treating physician is important. Additionally, trust in the treating physician has been found to increase patient enrollment in research studies (Bancroft et al., 2010; Kaiser et al., 2011). Enrolling patients into research studies will help the greater pancreatic cancer community in the future by allowing for discovery of new screening methods and treatments. Some participants noted that although they did not like the idea of undergoing screening, they trusted Dr. Brand's expertise and recommendations. Patients feel accountable for seeking medical care when they have an ongoing relationship with their doctor, which generally leads them to seek out further care for ongoing screening (Crooks et al., 2012).

Furthermore, patient-physician relationships is not the only important factor contributing to an overall positive patient experience; the support staff with whom patients also interact

allows for the establishment of a positive relationship (Andaleeb, 2001). Participants acknowledged the positive interactions they had with all staff members whenever they attend the high-risk clinic and appreciated being notified by the clinic when it was time to make their next appointment.

6.1.2 Consideration of Patients' Opinions

Research suggests that patients have more confidence in the treatment plan when their thoughts and opinions are considered and they have the opportunity to engage in the conversation as the plan is determined (Thorne et al., 2013). Therefore, physicians might want to gain a better understanding of how the patient wants to proceed (Carney et al., 2006). Garnering the trust of a patient allows for open conversation for further discussions of management in the future.

6.1.3 Empowered to Engage Family

A number of participants felt that they were provided with abundant information regarding their increased risk and what screening would aid in early detection. The participants felt confident in the knowledge they had gained from the clinic to approach other at-risk family members to explain their risks. They described the information being provided to them as positive, which is consistent with what other studies identify as being main concerns of patients who are at an increased risk for cancer or who already have been diagnosed (Gopie et al., 2012; Schildmann et al., 2013).

6.1.4 Providing Hope

One participant remarked that it gave her hope that her husband was seen in the clinic. Studies have suggested that the feeling of hope is a motivating factor to undergo treatments (Schildmann et al., 2013; Underhill et al., 2015). Conveying hope is also important to patients, whether that is regarding hope for early detection, hope for treatment and curative measures available, or hope that the medical staff will be there for a patient when entering into the end of life stage (Bensing et al., 2013). Allowing for open communication between doctors and patients helps to instill trust within that relationship. Schildmann et al. (2013) found hope to be an important motivating factor for patients who had already been diagnosed with pancreatic cancer to continue on with treatment during later stages. This hope is especially critical for pancreatic cancer cases which tend to carry a much more severe prognosis.

6.1.5 Staff Expertise

Research has shown that patients want to go to a well-known cancer center and be treated by experts in the field (Schildmann et al., 2013; Underhill et al., 2012; Underhill et al., 2015). This is consistent with the findings in the current study; participants expressed their satisfaction of having world-class facilities so close to home. Underhill et al. (2012) found that women who were at an increased risk of developing breast cancer sought out well-known cancer centers. The centers were attractive because they provided both screening options as well as connections to a treatment team should the patients ever develop cancer (Underhill et al., 2012). Participants often brought up that undergoing screening allowed for early diagnosis and should something be

found, then it could be dealt with in a quick manner. An additional advantage is that they would already have a care team in place with whom they were comfortable.

The participants expressed appreciation having the opportunity to be seen at the high-risk clinic. They highlighted areas where they think the clinic is doing well, which are consistent with previous research. The participants expressed that they feel Dr. Brand and the clinic staff care for them as a person and not just as a patient.

6.2 THEME 2: POTENTIAL BARRIERS

Research has suggested that cost is a significant barrier to accessing medical care (Lewis et al., 2009; Thomson & Siminoff, 2015). Financial barriers may be due to lack of insurance, large co-pays and/or deductibles. Participants in this study discussed cost as an obstacle to receiving genetic testing or pancreatic cancer screening.

A study conducted by Lewis et al. (2009) found that the participants' biggest deterrent for not seeking out screening for pancreatic cancer was the cost, even if insurance coverage was a resource available to them. Thomson and Siminoff (2015), describe the difference in survival rate between individuals with colorectal cancer who have insurance and those who do not, stating that those who were insured had a three-year survival rate of 71% whereas those who were uninsured only had a 53% survival rate. Thomson and Siminoff (2015) also discuss the worry about incurring high costs that family members may have to pay, which has been found to be a deterrent to seeking out care. Worry about incurring high costs to family members due to treatment was not brought up by the participants in the current study. It is unknown if this is something the participants have considered and did not bring up during the focus groups, or if it

is not a factor that is a cause for concern. Participants primarily discussed not being able to pay for the actual screening or genetic testing and not being able to receive the care that they felt they needed. Insurance coverage for pancreatic cancer screening proves to be a challenge because of the lack of formal guidelines for screening at risk individuals (Randall Brand, MD, personal communication).

Another potential barrier that may be present for some individuals is receiving misinformation from a health care provider. For example, one participant who has a *BRCA* pathogenic variant received inaccurate information from her obstetrician who told the participant that she was not at an increased risk for breast cancer because the breast cancers were coming from her father's side of the family and that she leads a lifestyle that helps in reducing risk, including eating healthfully, maintaining a healthy weight and breastfeeding her children. Although this participant was interested in receiving a mammogram, the physician said it was not necessary. A few years later she developed breast cancer. This finding is congruent with research conducted by Omran et al. (2014) and DudokdeWit et al. (1997) suggesting that not all physicians are up-to-date on the current information and screening guidelines for hereditary cancers, which can lead to their patients not receiving proper care. The American Society of Clinical Oncology (ASCO) has established guidelines for when a patient should receive a genetics consultation, the first relating to the patient having a family history that is suggestive of a genetic predisposition to developing cancer (Robson et al., 2010), including when there is breast cancer present on the paternal side of the family (Clinical, Guidelines, & Guidelines, 2016).

Thomson and Siminoff (2015) contend that other barriers must be present because there is incomplete uptake of screening in countries that have universal health care, such as Canada.

Additional barriers that have been described in other research include psychosocial barriers such as the fear of what may be seen on screening tests or learning that they have cancer (Hubbard et al., 2014). These are discussed further in the fear of developing cancer section. Additionally, another barrier could be the fear of the actual procedure itself and the level of invasiveness. Further discussion related to these potential barriers can be found in the expectations section.

6.3 THEME 3: FEAR OF DEVELOPING CANCER

Going through cancer, or knowing that one is at an increased risk of getting cancer can be difficult. Most people have been touched by cancer at some point in their life, and they may know someone who has passed away from it. It is only natural that people express feelings of fear when thinking about cancer, especially when they have watched a number of people die from cancer in their family. These feelings have the potential to become amplified when the cancer someone is at an increased risk of developing has a low survival rate. Some participants of the focus groups expressed feelings of fear.

The participants who were caregivers and also at an increased risk of developing pancreatic cancer expressed their fear of developing pancreatic cancer or what might be found during screening. Hubbard et al. (2014) and Saslow et al. (2007) found similar results in their study of patients seeking medical care in a cancer setting. Fear of the pain and suffering that can occur with cancer, as well as the fear of death were barriers that patients may have faced prior to seeking care (Hubbard et al., 2014; Saslow et al., 2007). Fear can be a driving factor for people who do and do not seek help in the realm of cancer (Hubbard et al., 2014). For people who have loved ones affected by cancer, this can be a motivating factor to seek out additional screening

(Breitkopf et al., 2012; Howell et al., 2013; Underhill et al., 2015); conversely, some people may want to avoid extra screening for fear that they too may be diagnosed with cancer and have to endure the same pain they observed in their loved one (Hubbard et al., 2014; Saslow et al., 2007). These differences may be due to various coping strategies that people utilize to help deal with their increased risk. Additionally, it has been shown that patients with an increased risk for developing breast and ovarian cancer who have an increased anxiety level correlates with an uptake in screening until the level of anxiety becomes too high, thus leading to an avoidance of screening (Antill et al., 2006; Meiser et al., 2000; Consedine et al., 2004).

One participant in the current study and another in Underhill et al. (2015) share the same sentiment about pancreatic cancer, that being at risk is like "a ticking time bomb," or that pancreatic cancer is a "death sentence." Such comments may relate to these participants' experiences watching loved ones pass away due to pancreatic cancer. These experiences can weigh heavily on family members and shape how they view pancreatic cancer (Heiniger et al., 2015; Underhill et al., 2015).

Participants who are patients of the high-risk clinic relayed that attending the clinic and having some form of screening provided them with hope should cancer be found; however, their caregivers, who were also at an increased risk found fear to be their driving force and was a deterrent for attending the clinic. The participants who spoke of seeing the clinic as a beacon of hope were apart of the older generation in their family, whereas those who spoke about being fearful of attending the clinic were of the younger generation. While hope may be a motivating factor for some of the participants, they may also feel fear as a motivating factor as well because they do not know what would be found at every appointment, but they hang onto hope that if something is found, it is found early. Participants who are incapacitated by fear may be unable to

see the hope that comes with attending the clinic because they can only see the possibility of what might be found.

6.4 THEME 4: FAMILY

Research has shown that seeking out medical attention can be motivated by having a family history of cancer (Lewis et al., 2009; Schwartz et al., 2003; Tong et al., 2015). Some participants in the current study noted that their families are a major support in their lives and this support serves as a motivating factor to undergo screening or to start screening. One husband exemplified the support a caregiver can provide by stating that he was willing to do anything to help his wife reduce her risk and receive additional screening. The comment by the husband supports the research of Howell et al. (2013) that characterizes the different forms of support that family members can offer, including emotional, educational, financial, and logistical support.

Several participants made comments about the loss of a loved one and how this motivated them to seek care at the clinic. This finding is consistent with the research by Underhill et al. (2015) and Lewis et al. (2009). In their studies they also found that participants tried to control their risk by increasing screening and adopting better lifestyle habits in hopes of not encountering the same fate as their loved ones.

A few of the participants expressed their frustration with family members who are not interested in attending the high-risk clinic and do not appear to worry about their risks. These participants stated that they wanted to find ways to encourage family members to get involved. The participants who expressed these frustrations were women, which aligns with previous research that women tend to be more in tune to the health behaviors of family members and

provide the extra motivation necessary for family members to seek out medical attention (E. K. Shaw et al., 2013). However, it could be possible that the male participants did not have other family members who are at an increased risk, or if they do, these family members are already seeking out increased care.

6.5 THEME 5: GOALS FOR THE CLINIC

Although the participants spoke highly of the clinic, they identified several areas they would like to see improved in pancreatic cancer research as well as one specific logistical issue for the high-risk clinic.

Many of the participants spoke about wanting to learn more information from the clinic. Participants want to learn what they could do to help reduce their risks of getting pancreatic cancer. Participants remarked that they wanted more information about foods they should eat, which ones they should avoid, and if they should take extra vitamins. Additionally, they wanted to learn more about the PAGER study and any discoveries from this research. These findings are consistent with what Underhill et al. (2015) found in their study of patients who have an increased risk for developing pancreatic cancer. Both the participants in the current study and in Underhill et al.'s (2015) recognized that not much is known about pancreatic cancer in comparison to other cancers and they wanted to know what they could do to best care for themselves and their families.

The desire to keep abreast of recent research discoveries may allow patients to feel empowered when living with an increased risk for cancer. The PEARL quarterly newsletter sent to patients appears to be an appropriate strategy for keeping patients up-to-date with what is

going on in the clinic as well as any other new research that is currently taking place. It may be worthwhile to look at increasing the publication volume from four in a year to six so patients feel they are getting the most information possible. Lewis et al. (2009) report on study participants who believe that there should be more public awareness about pancreatic cancer, available screening and help to assist people recognize if they are at an increased risk of developing it. Saslow et al. (2007) identify media and word-of-mouth as a good strategy of promoting cancer awareness and help-seeking behaviors. A recent study by Ghanouni et al. (2016) discuss the use of websites to help increase public knowledge about cancer-related health care as the majority of adults search health-related questions on the Internet. The National Organization for Rare Disorders (NORD) disseminates information about and advocates for various rare disorders and current research trials ("NORD (National Organization for Rare Disorders)," 2016). Similarly, the Pancreatic Cancer Action Network (PanCAN) provides information about pancreatic cancer, clinical trials, and supports advocacy for pancreatic cancer ("Pancreatic Cancer Action Network," 2016). Additionally, NORD provides support to various smaller organizations for specific conditions that are part of the greater NORD umbrella ("NORD (National Organization for Rare Disorders)," 2016).

Although some participants in this study felt that they were provided with enough information during their appointment to then relay to other family members, some felt that they needed more guidance or strategies to help family members see the importance of attending the high-risk clinic. One participant remarked that she would like web links to lectures presented by doctors she could send to various family members. This has been seen in other studies (Gaff et al., 2005; Green et al., 1997). Providing letters to family members outlining their increased risk

and the next steps to take have been discussed in different studies as an appropriate strategy to help facilitate familial communication (Claes et al., 2004; Green et al., 1997).

Participants expressed their desire for an easier method of screening that was quicker, cheaper, and less invasive. This finding is the same as what was found in Underhill et al. (2015), and holds true to similar findings within the high-risk breast and colon cancer populations (Gopie et al., 2012). In these studies (Gopie et al., 2012; Underhill et al., 2015), participants were satisfied that they were able to participate in screening; however, they preferred more accurate screening modalities. Patients may express uneasiness about the level of invasiveness of the screening; however, they noted that if a previous noninvasive, or less invasive test indicated the need for further evaluation, there was a higher likelihood that they would go forth with the more invasive test (Breitkopf et al., 2012; Lewis et al., 2009). Lewis et al. (2009) report patients' dissatisfaction for the time it takes to undergo the procedures as well as the recovery. People become more interested in screening when there is a doctor-recommended modality that is quick, easy, cheap all while still being accurate (Lewis et al., 2009). Lewis et al. (2009) found that patients preferred a non-invasive and cheap test (e.g. a blood test) that could be used for screening purposes.

Specifically related to the high-risk clinic in Pittsburgh, participants expressed concerns over difficulties getting their blood drawn either to be a part of the PAGER study or for genetic testing. They conveyed that there was not always a phlebotomist present to take their blood sample and there was a possibility that they would have to return another day to get the blood draw completed. One way to remedy this situation is to have at least one phlebotomist in the clinic at all times, which may not be practical if not all patients being seen need to have their blood taken. Another solution to explore is to direct patients to the main laboratory in the

hospital to get their blood drawn and having a process in place for the appropriate delivery of the blood specimen. Finally, if other staff members would undergo phlebotomy training, then there may not be a need for an additional full-time phlebotomist. However, a trained staff member would always need to be available in the clinic to take blood samples.

What was interesting about the focus groups was the supportive feel they had. There were many times during the focus groups when participants were supportive of one another, and it seemed as though they made a connection. This is not overly surprising since the participants share similar journeys, whether that is through providing care to a loved one who has or had cancer or is at an increased risk of developing pancreatic cancer, or they are a patient at the clinic because of their personal or familial cancer risks. From this finding, it might be reasonable to consider starting a support group with individuals who attend the High-Risk Pancreas Clinic.

6.6 LIMITATIONS

One limitation of this study is the population that participated within the focus groups. The vast majority of comments about the clinic were positive and it is possible that participants who were dissatisfied may not have felt comfortable to discuss their feelings of dissatisfaction with the clinic. In addition, people who attended the focus groups may be more open to discussing their risk than other individuals who did not participate in the focus groups. PAGER participants who are private about their increased risk for cancer may not have wanted to attend a focus group with other individuals.

Though some participants commented about family members who avoid the topic of pancreatic cancer and do not attend the clinic, this study does not address why people are not

interested in the clinic or if these individuals need something more from the clinic before they seek out care.

6.7 FUTURE STUDIES

There are a number of studies evaluating the risk perceptions of individuals who are at an increased risk for breast cancer (Dudokdewit et al., 1997; Epstein et al., 1997; Salant et al., 2006), but few (Silver, 2012) regarding the risk perceptions of individuals at risk of developing pancreatic cancer. It is important to further explore this area to help identify patient understanding of their personal risks. This can be achieved by administering a questionnaire inquiring about patients' perceived risks of developing pancreatic cancer based on family history or genotype before and after genetic counseling appointments to determine if risk perception becomes more accurate after counseling. Additionally, it would be beneficial to understand how patients feel before and after screenings for pancreatic cancer. For example, levels of anxiety could be measured and assess if levels of anxiety correlate with seeking out increased screening. Should significant levels of anxiety be identified, this information would be used to help identify ways for the clinic to better support patients during screening procedures. With regards to patient experience, doing larger research studies to examine patient satisfaction in high-risk pancreatic clinics would be important to determine the best way to care for at-risk individuals and their families. Smaller quality assurance studies periodically at the UPMC High-Risk Pancreas Clinic would help in continually meeting the needs of the patients. Studies surrounding the aforementioned topics could help in identifying how individuals at an increased risk for

pancreatic cancer cope with knowing that they are at an increased risk for a cancer that does not have a robust screening method, and has a high mortality rate.

6.8 PUBLIC HEALTH SIGNIFICANCE

This study has public health significance by identifying areas that lead to patient satisfaction that other high-risk cancer centers can employ which may lead to better health outcomes. The participants in the study spoke highly of the clinic, this is important to public health because when patients are satisfied with the care they receive from their doctor, they continue to seek care. If the patients are undergoing screening for pancreatic cancer, then there is the possibility that should cancer develop, it can be identified early and treatment can be sought. This has the potential to increase survival rates. Additionally, patients who attend high-risk clinics have opportunities to enroll in research studies, which can help in developing better screening and treatment modalities. This research also identifies areas that are lacking specifically for pancreatic cancer, for example the lack of formal screening guidelines for at risk individuals and the related challenge of getting adequate insurance coverage for this screening. As additional pathogenic variants are identified that are related to pancreatic cancer, it will be increasingly important to develop formalized screening guidelines so that the number of patients who do not receive insurance coverage for screening is diminished.

7.0 CONCLUSION

Pancreatic cancer is often a devastating diagnosis due to the high mortality rate. Many people who are at an increased risk of developing pancreatic cancer may feel at a loss as to where to turn. The UPMC High-Risk Pancreatic Clinic in Pittsburgh, Pennsylvania, provides an important service and allows individuals to learn about risks and increased screening that is available. Patients are pleased with the clinic, but they still hope that in the future there will be easier, cheaper, and more accurate screening modalities that will lead to a decrease in the mortality rate.

The literature is replete with studies that have examined patient experiences in high-risk clinics for breast and colorectal cancers (Bancroft et al., 2010; Gopie et al., 2012; Salant et al., 2006; Yacavone et al., 2001); however, very few have been done within the context of pancreatic cancer. This study serves to add to the pancreatic cancer literature, and as an additional resource in further improving and developing initiatives similar to PAGER that are designed to treat populations with a high pancreatic cancer risk.

APPENDIX A: IRB APPROVAL

University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508
(fax)
http://www.irb.pitt.edu

Memorandum

To: Dr. Randall Brand
From: Sue Beers , Ph.D., Vice Chair
Date: 7/26/2012
IRB#: PRO12070378
Subject: Focus Group for Patients with a Family History of Pancreatic Cancer

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The above-referenced project has been reviewed by the Institutional Review Board. Based on the information provided, this project meets all the necessary criteria for an exemption, and is hereby designated as "exempt" under section
45 CFR 46.101(b)(2) Tests, surveys, interviews, observations of public behavior

Please note the following information:

- If any modifications are made to this project, use the "**Send Comments to IRB Staff**" process from the project workspace to request a review to ensure it continues to meet the exempt category.
- Upon completion of your project, be sure to finalize the project by submitting a "**Study Completed**" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX B: PATIENT FOCUS GROUP GUIDE

Hi! I'm Martha from the University of Pittsburgh, and I'll be facilitating the discussion tonight. You've been invited to participate because you are a client at the High Risk Pancreas Clinic and have used its services. We'll be here for about an hour and a half talking about the clinic, what you like about it, things that the clinic could do for you and things the clinic could do better.

There are no right or wrong answers to the questions I'll be asking. We all come from different backgrounds and have different experiences, and that's what we want to hear about – opinions and knowledge that each of you has. What you have to tell me is valuable, because it will help staff at the clinic make changes to serve you better, and who better to ask than you, consumers of the services here. In other words, you're the experts. I'll be respectful of your answers and appreciate your being respectful of one another and keeping what is said in this room to yourselves. You can choose whether to answer questions or not.

We are audiotaping the discussion tonight. Once transcribed, the tape will be destroyed, and the transcript of the discussion will be stored on a protected server. Only researchers connected with the project will have access to the transcript, and no identifying information will be taken down. So there is no way to connect your comments with you as an individual, and when we report out on this work, we will do so in summary statements. By staying at the table you give your consent to be audiotaped and to have your comments used in any reports or articles that are published, without attribution of course.

We have food for you – please help yourselves; if you need to leave for any reason, you may do so. The restrooms are….. When we are done with our conversation we have a $25 gift card as a thank you for your time.

Please use the name tent to indicate what you want to be called tonight – you can use your own name or any name you like.

Any questions? Okay, let's begin.

1. First of all, tell me your name and where you currently live.
2. Think of a time when you have come to the clinic and tell me about that.
   Was it what you expected?
3. What is the clinic doing right? Are there things that could be done better, information you feel like you need (PROBE: nutrition, lifestyle)?
4. Tell me how having a history of pancreatic cancer in your family affects your life.
5. Are there things you have thought about that would help you with those issues?
6. Anything else you would like to add?

Thanks so much for sharing your thoughts with us tonight.

APPENDIX C: CAREGIVER FOCUS GROUP GUIDE

Hi! I'm Tammy from the University of Pittsburgh, and I'll be facilitating the discussion today. You've been invited to participate because you are a spouse or partner of a client at the High Risk Pancreas Clinic who has used its services. We'll be here for about an hour and a half talking about the clinic, what you like about it, things that the clinic could do for you and things the clinic could do better.

There are no right or wrong answers to the questions I'll be asking. We all come from different backgrounds and have different experiences, and that's what we want to hear about – opinions and knowledge that each of you has. What you have to tell me is valuable, because it will help staff at the clinic make changes to serve you and your loved one better. In other words, you're the experts. I'll be respectful of your answers and appreciate your being respectful of one another and keeping what is said in this room to yourselves. You can choose whether to answer questions or not.

We are audiotaping the discussion today. Once transcribed, the tape will be destroyed, and the transcript of the discussion will be stored on a protected server. Only researchers connected with the project will have access to the transcript, and no identifying information will be taken down. So there is no way to connect your comments with you as an individual, and when we report out on this work, we will do so in summary statements. By staying at the table

you give your consent to be audiotaped and to have your comments used in any reports or articles that are published, without attribution of course.

We have food for you – please help yourselves; if you need to leave for any reason, you may do so. The restrooms are….. .

Please use the name tent to indicate what you want to be called today– you can use your own name or any name you like.

Any questions? Okay, let's begin.

1. First of all, tell me your name and where you currently live.
2. Tell me about what you expected when you accompanied your spouse or partner the first time you came to the clinic.
3. How did the clinic live up to those expectations?
4. What is the clinic doing right? Are there things that could be done better, information you feel like you and your spouse or partner need (PROBE: nutrition, lifestyle)?
5. Tell me how having a loved one with pancreatic cancer affects your life.
6. Are there things you have thought about that would help you with those issues?
7. Anything else you would like to add?

Thanks so much for sharing your thoughts with us tonight.

APPENDIX D: CODEBOOK

Code	Where	Definition	Theme	Subtheme
Appointment reminders	Oct 1 patient pg12	Comments about making appointments with the clinic	Attributes of the clinic	Appointment reminders
Appointment reminders	Oct 1 patient pg14	Comments about making appointments with the clinic	Attributes of the clinic	Appointment reminders
Appointment reminders	Oct 1 spouse pg3	Comments about making appointments with the clinic	Attributes of the clinic	Appointment reminders
Appointment reminders	Oct 1 spouse pg4	Comments about making appointments with the clinic	Attributes of the clinic	Appointment reminders
High standard of care	Oct 1 patient pg14	Comments about the reputation of hospital and clinic	Attributes of the clinic	Bedside manner
High standard of care	Oct 18 pg12	Comments about the reputation of hospital and clinic	Attributes of the clinic	Bedside manner
High standard of care	Oct 18 pg26	Comments about the reputation of hospital and clinic	Attributes of the clinic	Bedside manner
Nice clinic staff	Oct 1 patient pg14	Comments about the staff	Attributes of the clinic	Bedside manner
Hope	Oct 1 patient pg13	Comments about having a better chance	Attributes of the clinic	Chance
Hope	Oct 1 patient pg3-4	Comments about having a better chance	Attributes of the clinic	Chance
Hope	Oct 18 pg28	Comments about having a better chance	Attributes of the clinic	Chance
Peace of mind	Oct 1 spouse pg5	Doing what you can	Attributes of the clinic	Chance
High standard of care	Oct 1 patient pg25	Comments about the reputation of hospital and clinic	Attributes of the clinic	Checklist
Relief	Oct 1 patient pg25	Comments about feeling that you are getting proper care	Attributes of the clinic	Checklist
Empowered	Oct 18 pg26	Feelings they could do things for themselves	Attributes of the clinic	Empowerment
Empowered	Oct 1 patient pg12	Feelings they could do things for themselves	Attributes of the clinic	Feelings about being seen at the clinic
Dedication of doctor	Oct 18 pg12	Comments about the time the doctor spent	Attributes of the clinic	Priority
Dedication of doctor	Oct 18 pg13	Comments about the time the doctor spent	Attributes of the clinic	Priority
Dedication of doctor	Oct 18 pg14	Comments about the time the doctor spent	Attributes of the clinic	Priority
Dedication of doctor	Oct 18 pg21	Comments about the time the doctor spent	Attributes of the clinic	Priority
High standard of care	Oct 18 pg11	Comments about the reputation of hospital and clinic	Attributes of the clinic	Quality staff
High standard of care	Oct 18 pg29	Comments about the reputation of hospital and clinic	Attributes of the clinic	Quality staff
Satisfaction	Oct 18 pg14	Comments that express satisfaction with the clinic	Attributes of the clinic	Quality staff
Satisfaction	Oct 18 pg26	Comments that express satisfaction with the clinic	Attributes of the clinic	Quality staff
Clinic still there for you	Oct 1 patient pg13	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg13	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg13	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg13	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg13	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg13	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg14	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg29	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg29	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 1 patient pg6	Always being able to turn to the clinic	Attributes of the clinic	There for you
Clinic still there for you	Oct 18 pg11	Always being able to turn to the clinic	Attributes of the clinic	There for you
Time to do procedures	Oct 1 patient pg14	Length of time	Attributes of the clinic	Time conscious
Time to do procedures	Oct 1 patient pg14	Length of time	Attributes of the clinic	Time conscious

I feel safe here	Oct 18 pg27	Comments about feeling safe	Attributes of the clinic	Trust
Advocates for patients	Oct 18 pg11	Speaks to other doctors to help appointment scheduling	Attributes of the clinic	
Educating	Oct 1 patient pg13	Comments about education they got at the clinic	Attributes of the clinic	
Educating	Oct 18 pg10	Comments about education they got at the clinic	Attributes of the clinic	
Educating	Oct 18 pg12	Comments about education they got at the clinic	Attributes of the clinic	
Educating	Oct 18 pg14	Comments about education they got at the clinic	Attributes of the clinic	
Educating	Oct 18 pg14	Comments about education they got at the clinic	Attributes of the clinic	
Educating	Oct 18 pg18	Comments about education they got at the clinic	Attributes of the clinic	
Educating	Oct 18 pg26	Comments about education they got at the clinic	Attributes of the clinic	
High standard of care	Oct 18 pg27	Comments about the reputation of hospital and clinic	Attributes of the clinic	
High standard of care	Oct 18 pg27	Comments about the reputation of hospital and clinic	Attributes of the clinic	
High standard of care	Oct 18 pg29	Comments about the reputation of hospital and clinic	Attributes of the clinic	
In touch during surgery	Oct 18 pg5	Comments about how staff would keep in touch with family during surgery	Attributes of the clinic	
In touch during surgery	Oct 18 pg5	Comments about how staff would keep in touch with family during surgery	Attributes of the clinic	
In touch during surgery	Oct 18 pg5	Comments about how staff would keep in touch with family during surgery	Attributes of the clinic	
Informative	Oct 18 pg21	Level of information provided	Attributes of the clinic	
Kind staff	Oct 18 pg12	Comments about the staff	Attributes of the clinic	
Pearl	Oct 18 pg16	Comments about the Pearl	Attributes of the clinic	
Review tests to be done	Oct 18 pg11	Review with patients	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg10	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg11	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg12	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg17	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg2	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg2	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg3	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg4	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg4	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg5	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 1 spouse pg9	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 18 pg10	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 18 pg14	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 18 pg14	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 18 pg26	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 18 pg33	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 18 pg5	Comments that express satisfaction with the clinic	Attributes of the clinic	
Satisfaction	Oct 18 pg6	Comments that express satisfaction with the clinic	Attributes of the clinic	
Working with patient needs and v	Oct 1 patient pg9	Listening to patient concerns	Attributes of the clinic	
Family considerations	Oct 18 pg6	Involving family in decision	Family dynamics	Considers family
Didn't seek care	Oct 1 spouse pg20	Family members not seeking care before diagnosis	Family dynamics	
Family involvement	Oct 1 spouse pg5	Getting family involved with clinic	Family dynamics	
Frustration with family	Oct 1 patient pg10	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 patient pg10	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 patient pg27	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 spouse pg14	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 spouse pg15	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 spouse pg15	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 spouse pg2	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 spouse pg4	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 1 spouse pg4	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 18 pg22	Frustation was conveyed on audiotape	Family dynamics	
Frustration with family	Oct 18 pg9	Frustation was conveyed on audiotape	Family dynamics	
Haven't had cancer yet	Oct 18 pg2	Only one who hasn't had cancer in family	Family dynamics	
Life events change mind for testi	Oct 1 patient pg27	Deciding to undergo testing after new diagnoses	Family dynamics	
Loss before death	Oct 1 spouse pg14	Realizing big events in the year might be the last ones	Family dynamics	
Lost/confusion	Oct 1 patient pg13	Feelings of losing loved one	Family dynamics	
Not completely open with diagno	Oct 1 patient pg11	Finding out diagnosis of family member years later	Family dynamics	
Providing care	Oct 1 patient pg12	Experiences providing care to loved one	Family dynamics	
Providing care	Oct 1 spouse pg14	Experiences providing care to loved one	Family dynamics	
Providing care	Oct 1 spouse pg14	Experiences providing care to loved one	Family dynamics	
Providing care	Oct 18 pg22	Experiences providing care to loved one	Family dynamics	
Providing care	Oct 18 pg4	Experiences providing care to loved one	Family dynamics	
Testing can affect children's lives	Oct 1 patient pg28	Affect of knowing about familial mutation on children's lives	Family dynamics	
Timing to tell kids about mutatio	Oct 1 patient pg28	Not fair to tell kids about mutation	Family dynamics	
Wants kids to be tested once of a	Oct 1 patient pg28	Desire of kids to be tested once old enough	Family dynamics	
Wouldn't listen to doctor	Oct 1 spouse pg14	Not listening to doctor recommendations	Family dynamics	
Emotional aspect	Oct 18 pg21	Feelings surrounding screening	Feelings	Feelings about being seen at the clinic
Emotional aspect	Oct 18 pg21	Feelings surrounding screening	Feelings	Feelings about being seen at the clinic
Fear	Oct 1 patient pg9	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear	Oct 1 spouse pg12	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear	Oct 1 spouse pg12	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear	Oct 18 pg10	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear	Oct 18 pg21	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear	Oct 18 pg4	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear	Oct 18 pg4	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear	Oct 18 pg9	Any comment describing the fear they feel	Feelings	Feelings of being at risk

Fear for kids' results	Oct 1 patient pg27	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Fear/ uncertainity	Oct 1 patient pg3	Any comment describing the fear they feel	Feelings	Feelings of being at risk
Have to deal with it	Oct 1 spouse pg12	Coping with being at risk	Feelings	Feelings of being at risk
Have to deal with it	Oct 1 spouse pg12	Coping with being at risk	Feelings	Feelings of being at risk
Have to deal with it	Oct 1 spouse pg12	Coping with being at risk	Feelings	Feelings of being at risk
Have to deal with it	Oct 1 spouse pg13	Coping with being at risk	Feelings	Feelings of being at risk
Have to deal with it	Oct 1 spouse pg14	Coping with being at risk	Feelings	Feelings of being at risk
Have to deal with it	Oct 18 pg24	Coping with being at risk	Feelings	Feelings of being at risk
Time bomb	Oct 1 patient pg28	Feeling of being at risk	Feelings	Feelings of being at risk
Relief	Oct 1 spouse pg14	Comments about feeling that you are getting proper care	Feelings	Relief
How to provide info to family	Oct 1 spouse pg2	Comments around explaining risks to other family members	Looking to get from clinic	
How to provide info to family	Oct 1 spouse pg6	Comments around explaining risks to other family members	Looking to get from clinic	
How to provide info to family	Oct 18 pg15	Comments around explaining risks to other family members	Looking to get from clinic	
How to provide info to family	Oct 18 pg15	Comments around explaining risks to other family members	Looking to get from clinic	
How to provide info to family	Oct 18 pg21	Comments around explaining risks to other family members	Looking to get from clinic	
How to provide info to family	Oct 18 pg21	Comments around explaining risks to other family members	Looking to get from clinic	
Info seeking	Oct 1 spouse pg5	Looking for different forms of information	Looking to get from clinic	
Info seeking - beneficial	Oct 1 spouse pg11	Comments gathering people's opinions	Looking to get from clinic	
Info seeking - cost	Oct 1 spouse pg12	Info about insurance coverage	Looking to get from clinic	
Info seeking - genetics	Oct 1 patient pg25	Questions regarding genetics of cancer	Looking to get from clinic	
Info seeking - genetics	Oct 18 pg13	Questions regarding genetics of cancer	Looking to get from clinic	
Info seeking - genetics	Oct 18 pg20	Questions regarding genetics of cancer	Looking to get from clinic	
Info seeking - new research	Oct 1 patient pg16	Questions about new reasearch being done	Looking to get from clinic	
Info seeking - new research	Oct 1 patient pg30	Questions about new reasearch being done	Looking to get from clinic	
Info seeking - new research	Oct 1 spouse pg10	Questions about new reasearch being done	Looking to get from clinic	
Info seeking - new research	Oct 1 spouse pg3	Questions about new reasearch being done	Looking to get from clinic	
Info seeking - protect self	Oct 1 patient pg3	Questions about ways to be proactive in protecting self	Looking to get from clinic	
Info seeking - study	Oct 1 spouse pg8	Questions about PAGER study	Looking to get from clinic	
Info seeking - study	Oct 18 pg28	Questions about PAGER study	Looking to get from clinic	
Lifestyle info - diet	Oct 1 patient pg9	Comments about diet and risk	Looking to get from clinic	
Lifestyle info - diet	Oct 1 spouse pg7	Comments about diet and risk	Looking to get from clinic	
Lifestyle info - diet	Oct 18 pg17	Comments about diet and risk	Looking to get from clinic	
Lifestyle info - exposures	Oct 1 patient pg20	Comments about exposures for increased risk	Looking to get from clinic	
Lifestyle info - exposures	Oct 1 patient pg4	Comments about exposures for increased risk	Looking to get from clinic	
Lifestyle info - exposures	Oct 1 patient pg4	Comments about exposures for increased risk	Looking to get from clinic	
Looking for answers	Oct 1 patient pg12	Reasons for why family members got cancer	Looking to get from clinic	
Looking for answers	Oct 18 pg20	Reasons for why family members got cancer	Looking to get from clinic	
More staff needed	Oct 18 pg10	Phlebotomists needed	Looking to get from clinic	
More staff needed	Oct 18 pg12	Phlebotomists needed	Looking to get from clinic	
New research	Oct 1 patient pg20	Inquiries about new research	Looking to get from clinic	
New research	Oct 1 patient pg26	Inquiries about new research	Looking to get from clinic	
New research	Oct 1 patient pg26	Inquiries about new research	Looking to get from clinic	
New research	Oct 1 patient pg30	Inquiries about new research	Looking to get from clinic	
New research	Oct 1 patient pg4	Inquiries about new research	Looking to get from clinic	
New research	Oct 1 spouse pg10	Inquiries about new research	Looking to get from clinic	
New research	Oct 1 spouse pg2	Inquiries about new research	Looking to get from clinic	
That's what I want	Oct 1 spouse pg5	Want out of screening	Looking to get from clinic	
Updating	Oct 1 spouse pg10	Want updates on research/ new info	Looking to get from clinic	
Updating	Oct 1 spouse pg4	Want updates on research/ new info	Looking to get from clinic	
Want more info	Oct 18 pg16	Additional info	Looking to get from clinic	
Concern for family	Oct 1 patient pg24	Comments about risks for other family members	Motivation to attend clinic	
Concern for family	Oct 1 patient pg25	Comments about risks for other family members	Motivation to attend clinic	
Concern for family	Oct 1 spouse pg9	Comments about risks for other family members	Motivation to attend clinic	
Concern for own risk	Oct 1 patient pg28	Comments about risks for self	Motivation to attend clinic	
Concern for own risk	Oct 1 spouse pg2	Comments about risks for self	Motivation to attend clinic	
Concern for own risk	Oct 1 spouse pg9	Comments about risks for self	Motivation to attend clinic	
Expectations	Oct 1 spouse pg2	Statements about what they were expecting	Motivation to attend clinic	
Expectations	Oct 18 pg10	Statements about what they were expecting	Motivation to attend clinic	
Findings	Oct 1 spouse pg11	Screening findings	Motivation to attend clinic	
Findings	Oct 1 spouse pg3	Screening findings	Motivation to attend clinic	
First with new info	Oct 1 spouse pg10	Getting new info because in study	Motivation to attend clinic	
Genetic testing	Oct 1 patient pg22	Comments about genetic testing participants underwent	Motivation to attend clinic	
Genetic testing	Oct 1 patient pg3	Comments about genetic testing participants underwent	Motivation to attend clinic	
Genetic testing	Oct 1 patient pg7	Comments about genetic testing participants underwent	Motivation to attend clinic	
Genetic testing	Oct 18 pg14	Comments about genetic testing participants underwent	Motivation to attend clinic	
Genetic testing	Oct 18 pg4	Comments about genetic testing participants underwent	Motivation to attend clinic	
Helping future patients	Oct 1 patient pg12	Comments contributing to research for future patients	Motivation to attend clinic	
Helping future patients	Oct 1 spouse pg10	Comments contributing to research for future patients	Motivation to attend clinic	
Helping future patients	Oct 18 pg21	Comments contributing to research for future patients	Motivation to attend clinic	
Helping future patients	Oct 18 pg29	Comments contributing to research for future patients	Motivation to attend clinic	
Motivation	Oct 1 patient pg12	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 1 patient pg16	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg12	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg3	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg3	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg3	Comments for why they go to clinic or do screeening	Motivation to attend clinic	

Motivation	Oct 18 pg4	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg4	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg6	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg6	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Motivation	Oct 18 pg8	Comments for why they go to clinic or do screeening	Motivation to attend clinic	
Not much you can do	Oct 1 spouse pg5	Acknowledging limitations of screening	Motivation to attend clinic	
Preventative surgery	Oct 1 patient pg7	Comments about surgeries done to reduce risk	Motivation to attend clinic	
Preventative surgery	Oct 1 patient pg9	Comments about surgeries done to reduce risk	Motivation to attend clinic	
Preventative surgery	Oct 18 pg4	Comments about surgeries done to reduce risk	Motivation to attend clinic	
Proactive	Oct 1 spouse pg12	Comments about proactively taking care of self	Motivation to attend clinic	
Proactive	Oct 1 spouse pg15	Comments about proactively taking care of self	Motivation to attend clinic	
Proactive	Oct 1 spouse pg9	Comments about proactively taking care of self	Motivation to attend clinic	
Proactive	Oct 18 pg16	Comments about proactively taking care of self	Motivation to attend clinic	
Proactive with surgery	Oct 18 pg22	Comments about proactively taking care of self	Motivation to attend clinic	
Ways to protect self	Oct 1 patient pg18	Comments made that are looking for ways to protect self or early detection	Motivation to attend clinic	
Ways to protect self	Oct 1 patient pg20	Comments made that are looking for ways to protect self or early detection	Motivation to attend clinic	
Ways to protect self	Oct 1 spouse pg2	Comments made that are looking for ways to protect self or early detection	Motivation to attend clinic	
Ways to protect self	Oct 18 pg18	Comments made that are looking for ways to protect self or early detection	Motivation to attend clinic	
Ways to protect self	Oct 18 pg29	Comments made that are looking for ways to protect self or early detection	Motivation to attend clinic	
Ways to protect self	Oct 18 pg4	Comments made that are looking for ways to protect self or early detection	Motivation to attend clinic	
Concern about insurance	Oct 1 patient pg27	Lose insurance coverage if positive for a mutation	Potential barriers	
Cost	Oct 1 patient pg24	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost	Oct 1 patient pg26	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost	Oct 1 patient pg29	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost	Oct 1 spouse pg12	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost	Oct 18 pg12	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost	Oct 18 pg27	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost - want to do screening but c	Oct 18 pg12	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost is barrier to genetic testing	Oct 1 patient pg27	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost of enzymes	Oct 18 pg6	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost of enzymes	Oct 18 pg7	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost of genetic testing	Oct 18 pg10	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Cost of medication	Oct 18 pg7	Comments regarding cost of screening, genetic testing, treatment	Potential barriers	
Procrastination	Oct 1 patient pg6	Slow to follow-up with clinic	Potential barriers	
Procrastination	Oct 1 spouse pg4	Slow to follow-up with clinic	Potential barriers	
Procrastination	Oct 18 pg9	Slow to follow-up with clinic	Potential barriers	
Uncertainty	Oct 1 patient pg24	Not knowing what will be found on screening	Potential barriers	
Shock by diagnosis	Oct 1 spouse pg14	Comments about not understanding the cancer diagnosis	Timing surrounding diagnosis	Unexpected
Shock of diagnosis	Oct 1 spouse pg14	Comments about not understanding the cancer diagnosis	Timing surrounding diagnosis	Unexpected
Shock of diagnosis	Oct 1 spouse pg15	Comments about not understanding the cancer diagnosis	Timing surrounding diagnosis	Unexpected
Shock of diagnosis	Oct 1 spouse pg15	Comments about not understanding the cancer diagnosis	Timing surrounding diagnosis	Unexpected
Shock of diagnosis	Oct 1 spouse pg15	Comments about not understanding the cancer diagnosis	Timing surrounding diagnosis	Unexpected
Shock of diagnosis	Oct 1 spouse pg15	Comments about not understanding the cancer diagnosis	Timing surrounding diagnosis	Unexpected
Delayed diagnosis	Oct 1 patient pg22	Comments about time it took for a diagnosis	Timing surrounding diagnosis	
Delayed diagnosis	Oct 1 patient pg23	Comments about time it took for a diagnosis	Timing surrounding diagnosis	
Early detection	Oct 1 spouse pg12	Comments about finding cancer early	Timing surrounding diagnosis	
Early detection	Oct 1 spouse pg3	Comments about finding cancer early	Timing surrounding diagnosis	
Early detection	Oct 18 pg23	Comments about finding cancer early	Timing surrounding diagnosis	
Early detection	Oct 18 pg4	Comments about finding cancer early	Timing surrounding diagnosis	
Early detection	Oct 18 pg4	Comments about finding cancer early	Timing surrounding diagnosis	
Early detection	Oct 18 pg9	Comments about finding cancer early	Timing surrounding diagnosis	
Hard to diagnose	Oct 1 patient pg22	Comments about the difficulty of making a diagnosis	Timing surrounding diagnosis	
Hard to diagnose	Oct 1 patient pg22-2	Comments about the difficulty of making a diagnosis	Timing surrounding diagnosis	
Hard to diagnose	Oct 1 patient pg25	Comments about the difficulty of making a diagnosis	Timing surrounding diagnosis	
Late diagnosis	Oct 1 patient pg28	Comments about the time it took for a diagnosis	Timing surrounding diagnosis	
Late diagnosis	Oct 1 patient pg7	Comments about the time it took for a diagnosis	Timing surrounding diagnosis	
Late diagnosis	Oct 1 spouse pg13	Comments about the time it took for a diagnosis	Timing surrounding diagnosis	
Late diagnosis	Oct 1 spouse pg3	Comments about the time it took for a diagnosis	Timing surrounding diagnosis	
Fluke	Oct 1 patient pg3	Didn't see pattern of cancer diagnoses in family		
Future screening	Oct 1 patient pg28	The advancement and future of screening for pancreatic cancer		
High hopes for easy screening	Oct 1 spouse pg5	Looking for easier screening methods		
Involved with the cause	Oct 1 patient pg16	Comments about being involved with the cause to bring awareness		
Involved with the cause	Oct 1 patient pg17	Comments about being involved with the cause to bring awareness		
Involved with the cause	Oct 1 patient pg29	Comments about being involved with the cause to bring awareness		
Involved with the cause	Oct 18 pg22	Comments about being involved with the cause to bring awareness		
Involved with the cause	Oct 18 pg28	Comments about being involved with the cause to bring awareness		
Many doctors	Oct 1 patient pg17	Seeing a number of doctors when diagnosed with cancer		
Misinformation	Oct 1 patient pg28	Another provider is not up to date on guidelines		
Not enough research	Oct 1 patient pg29	Lagging in pancreatic cancer research		
Not recognizing signs of cancer	Oct 18 pg23	Signs of cancer patients thought were due to other life events		
Number of screenings/tests	Oct 18 pg11	A number of different screenings the patient undergoes		
Overwhelmed, a lot going on	Oct 1 patient pg3	Comments about experiencing a lot in life at once		
Overwhelmed, a lot going on	Oct 1 patient pg3	Comments about experiencing a lot in life at once		
Overwhelmed, a lot going on	Oct 1 patient pg3	Comments about experiencing a lot in life at once		
Overwhelmed, a lot going on	Oct 1 spouse pg4	Comments about experiencing a lot in life at once		
Overwhelmed, a lot going on	Oct 18 pg29	Comments about experiencing a lot in life at once		
Overwhelmed,a lot going on	Oct 1 patient pg22	Comments about experiencing a lot in life at once		
Pancreatic statistics	Oct 1 patient pg29	Comments about statistics surrounding pancreatic cancer		
Pancreatic statistics	Oct 1 patient pg29	Comments about statistics surrounding pancreatic cancer		
Pancreatic statistics	Oct 1 patient pg29	Comments about statistics surrounding pancreatic cancer		
Pancreatic statistics	Oct 1 patient pg29	Comments about statistics surrounding pancreatic cancer		
Pancreatic statistics	Oct 18 pg16	Comments about statistics surrounding pancreatic cancer		
Pancreatic statistics	Oct 18 pg16	Comments about statistics surrounding pancreatic cancer		
Pancreatic statistics	Oct 18 pg27	Comments about statistics surrounding pancreatic cancer		
Potential symptoms	Oct 1 patient pg10	Questioning symptoms		
Reports on testing	Oct 1 spouse pg5	Results of screening discussed		
Resources	Oct 1 spouse pg7	Gathering information, getting connected in the pancreatic cancer community		
Surprise	Oct 18 pg25	Unexpected diagnosis		

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